

Clients' and Carers' Experiences of an Early Intervention for Psychosis Service

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degree of Doctor of Clinical Psychology**

South Wales Doctoral Programme in Clinical Psychology

DECLARATION

This work has not been previously accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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ABSTRACT

Early Intervention Services (EISs) for Psychosis have developed rapidly over the past decade. They offer support to people aged between 14-35 years of age with a first presentation of psychotic symptoms or during the first three years of psychotic illness. A plethora of research has explored the effectiveness of the EIS approach in terms of clinical outcomes, but few studies have explored clients' and carers' experiences of such services. This study focussed on clients' and carers' views and experiences of an EIS.

Semi-structured interviews were conducted with 13 participants (8 clients and 5 carers) who had been involved with an EIS for at least six months. The data were collected and analysed using a Grounded Theory approach. The analysis suggested that the experiences of participants could be portrayed in terms of three interrelated core categories: i) 'Engagement' – comprised of factors that help or hinder engagement with the service; ii) 'Ongoing involvement' – comprised of factors that challenge or support continued involvement with the service (and with the client's recovery); and iii) 'Towards Independence' – comprised of factors that help or hinder the process of moving on and the transition from service involvement towards independence. A varied list of personal, staff and service factors appeared to be related to various aspects of the three core categories.

Findings from this study are discussed in terms of their clinical implications. It is suggested that the effectiveness of EIS provision might be enhanced by promoting awareness of mental health difficulties and the availability of this type of service, providing training to EIS staff and allied professionals, and encouraging the delivery of interventions targeted specifically at carers. It is suggested that future research could usefully explore the experiences of other people who may play an important role in the lives of those experiencing first episode psychosis, including mental health professionals, siblings and peers.

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CHAPTER ONE: INTRODUCTION

1.1 THESIS OVERVIEW

This thesis reports a study conducted to explore clients' and carers' experiences of an Early Intervention for Psychosis Service (EIS). Chapter One provides an overview of background information regarding psychosis and EISs, a systematic review of the literature pertaining specifically to clients' and carers' experiences of EISs and the rationale for the study. Chapter Two addresses the research methodology, providing justification for the choice of the research paradigm, and outlining the sampling method, and the process of data collection and analysis. Issues of ensuring quality in qualitative research and ethical considerations are also discussed. Chapter Three presents the results of the qualitative Grounded Theory (GT) (Strauss and Corbin, 1990) analysis of the data collected from 13 participants interviewed about their experiences of an EIS. The analysis led to the identification of three core categories: 1. 'Engagement', 2. 'Ongoing involvement', and 3. 'Towards Independence'. These are presented in a series of hierarchical relationships involving **CORE CATEGORIES**, **categories**, sub-categories, and *concepts*. Chapter Four discusses the research findings in relation to the literature identified in Chapter One and additionally provides a discussion of the limitations of the study and implications arising from the study in relation to clinical practice, policy and research.

1.2 CHAPTER OVERVIEW

This chapter will, firstly, provide an overview of background information regarding psychosis and EISs. This will incorporate a review of the relevant literature, including national policies and research regarding the impact of psychosis on individuals and their families/carers, EISs' development and delivery, and issues of effectiveness and efficacy. In addition, a systematic review of the literature specifically relating to clients' and carers' views, and their experiences and satisfaction with the EIS is also provided. The rationale for exploring clients' and carers' experiences of an EIS will also be fully described.

1.3 BACKGROUND INFORMATION TO THE PRESENT STUDY

In this section, information regarding the definition and the impact of psychosis, both on the individual and the carer, will be outlined (section 1.3). A review of EISs' policy, guidance and effectiveness will also be provided (section 1.4).

1.3.1. Definition of Psychosis

Whilst the term 'psychosis' has received many definitions, none has been universally accepted. Nevertheless, in general, 'psychosis' typically refers to 'a disturbance in a person's thinking that divorces them from their surrounding reality' (Sainsbury Centre for Mental Health, (SCMH) 2003, p. 15) and is viewed as a *symptom* of mental health difficulties, rather than a diagnosis *per se* (Tsuang *et al.*, 2000).

According to the International Statistical Classification of Diseases and Related Health Problems (ICD 10) (World Health Organisation (WHO), 1992), 'psychosis' refers to a number of symptoms that are observable across a range of mental health problems, including 'manic depressive psychosis', 'bipolar affective disorder', 'schizophrenia', and 'paranoid schizophrenia'. Similarly, within the Diagnostic and Statistical Manual of Mental Disorders (DSM IV-TR) (American Psychiatric Association (APA), 2000) the term 'psychotic' refers to a specific set of symptoms within the diagnostic categories: 'schizophrenia', 'schizophreniform disorder', 'schizoaffective disorder' and 'brief psychotic disorder'. The symptoms across the ICD 10 (WHO, 1992) and the DSM IV- TR (APA, 2000) are broadly similar and include 'positive symptoms', such as distorted sensory perceptions (hallucinations), false paranoid or grandiose beliefs (delusions), disorganised speech, disorganised behaviour and 'negative symptoms', such as flat affect, reduced speech fluency and avolition.

First episode psychosis (FEP) refers to 'the first time a person experiences either the psychotic symptoms or a psychotic episode' (Sainsbury Centre for Mental Health (SCMH), 2003, p. 15). Whilst there are differing thresholds for FEP, a widely used definition suggests it is 'the first period lasting more than one week in which psychotic symptoms were present most of the time' (de Haan *et al.*, 2001, p. 84). Whilst a significant number of individuals with FEP are later diagnosed with schizophrenia (Edwards *et al.*, 1998), labelling an individual with this diagnosis prematurely may be detrimental, as this may either prove to be

inaccurate, since 40% of FEP diagnoses are altered after 18 months (McGorry and Yung, 2003), and/or result in stigma and distress for the individual and their family (Phelan *et al.*, 1999). Furthermore, many have contested whether schizophrenia, as a single prototypical disorder, does exist as it consists of ‘multiple syndromes and a myriad of underlying aetiopathologies’ (McGorry, 2000, p. 18). Thus, it is increasingly considered more helpful to refer to psychosis, rather than particular diagnoses, for those individuals who utilise the EIS (SCMH, 2003).

1.3.1.1 Phases of Psychosis

Increasingly, psychosis is viewed as having four phases (J. Baird, personal communication, 20 November 2011; McGorry and Edwards, 1997). These are detailed below and include:

- *The Prodromal phase* - a period prior to the development of psychotic symptoms, featuring early warning signs, which are usually identified with hindsight. Early warning signs may include mood swings, appetite or sleep changes;
- *The Acute phase* - a period characterised by positive symptoms e.g. hallucinations, delusions and thought disorder;
- *The Early recovery phase* - the first six months post acute treatment and intervention; and
- *The Late recovery phase* - the period following the early recovery phase for up to eighteen months.

1.3.2 Aetiology of Psychosis

A universally accepted causal pathology for psychosis has not been identified (Chua and McKenna, 1995). However, evidence suggests that it may be associated with a range of factors, such as stressful life events e.g. bereavement (Nuechterlein *et al.*, 1992), substance misuse (Cantwell *et al.*, 1999) and biological determinants, such as genetic predisposition (Carlsson, 1988).

More recently, it has generally been accepted that psychosis is multi-factorial and may be precipitated by a combination of environmental (biological and/or psychological) processes (e.g. substance misuse, stressful life events, hostile environments) and a genetic

predisposition to biological vulnerability. This explanatory model of psychosis is commonly known as the ‘stress-vulnerability’ model (Nuechterlein and Dawson, 1984). However, despite the increasing evidence base and widespread adoption of the model within clinical settings to inform interventions (Garety, 2003), some criticisms of the model remain. These criticisms suggest that the model largely ignores contextual factors such as neglect, trauma and poverty and additionally that the biological model has colonised the psychological and social models as environmental processes are simply triggers to an underlying genetic disposition (Read, 2005). Nonetheless, such a model does provide a useful framework for the management of psychosis which includes psychotherapy and psychosocial treatments in addition to pharmacology.

1.3.3 Incidence and Prevalence of Psychosis

According to the World Health Organisation (WHO, 2002) severe mental disorders, including schizophrenia and other forms of psychoses, represent a significant public health problem. Indeed, the WHO (2002) indicated that such disorders rank as the third most disabling condition and create a significant burden related to both cost and human suffering.

Despite a paucity of epidemiological research on psychosis, it appears that psychotic illnesses, such as schizophrenia and bipolar disorder, typically have their onset during adolescence and affect both genders equally (Singleton *et al.*, 2001). However, schizophrenia may be more likely to occur in males during their late teenage years (Russell *et al.*, 1989) which means that the onset of this illness is often during a critical period in a person’s development (Department of Health (DoH), 2001). The duration of psychosis is variable, and may, dependent on the cause, last from several hours to a number of years (SCMH, 2003).

The average incidence of psychosis varies between sources but it felt to lie within approximately 15 to 50 per 100,000 new cases per annum (Cheng *et al.*, 2011; DoH, 2001). However, this may vary with urbanicity and deprivation (Jenkins, 1998). Thus, in the UK, about 212, 000 people between the ages of 16-74 are likely to have a diagnosis of psychosis (Singleton *et al.*, 2001).

1.3.4 The Duration of Untreated Psychosis and the ‘Critical Period’

The duration of untreated psychosis (DUP) is ‘the time-lag between the onset of psychotic symptoms and the point at which treatment is provided’ (SCMH, 2003, p.19). A systematic

review investigating the association between DUP and outcome in cohorts of FEP patients found a mean DUP of over two years (Marshall *et al.*, 2005). A limited number of studies found no association between DUP and clinical outcome (Craig, 2000; de Haan *et al.*, 2000). However, others demonstrated that DUP is associated with increased risk of relapse (Crow *et al.*, 1986), psychosocial decline (Jones *et al.*, 1993), prolonged morbidity (McGorry, 1997), a deterioration in brain function (Wyatt, 1991), and unemployment, reduced social network and poor self esteem (Jackson and Falmer, 1998) (see section 1.4.5.2 for an in-depth discussion regarding the association between DUP and clinical outcome).

As indicated earlier, the average DUP is relatively lengthy (Marshall *et al.*, 2005) and may be as a result of many factors, such as stigma (Malla *et al.*, 1999) and the limited knowledge of those affected (SCMH, 2003), their families (de Haan, 2002) and health professionals (SCMH, 2003). However, this treatment delay is perceived to be important as the:

... cognitive and psychosocial (e.g. relationships, education, work) damage caused by psychosis occurs mainly during the early stages of psychosis, for a duration of up to five years, after which a plateau of disability is reached and little or no further deterioration occurs (Lieberman, 1997, cited in SCMH, 2003, p. 20).

Thus this early phase of high vulnerability has been termed the ‘critical period’ (Birchwood *et al.*, 1998).

Despite some evidence challenging the notion of a critical period (Carpenter and Strauss, 1991; Norman and Malla, 2001), a significant body of evidence supporting the proposition that the early phase of psychosis is a critical stage is summarized by Birchwood *et al.* (1998) and indicates that major psychosocial changes occur within the first three years of the disorder. Further long term follow up studies also provide support for the critical period hypothesis, indicating that outcomes (e.g. employment, symptoms) at two years are predictive of outcomes 15 years later (Harrison *et al.*, 2001). In addition, intervention within this period is suggested to decrease the risk of relapse and psychological difficulties (McGorry and Jackson, 1999), to improve service engagement and to prevent repeated relapses (Harrison *et al.*, 2001). Thus, in general, the first five years after the onset of psychosis are considered as a critical period for recovery (Canadian Mental Health Association, 2000).

1.3.5 Impact of Psychosis on the Individual

The impact of psychosis on the individual may be devastating. Frequently, evidence suggests that individuals in the acute phase often struggle to make sense of their experiences, leading to confusion, fear and a sense of loss of control (Kilkku *et al.*, 2003). Indeed, positive symptoms, such as hallucinations or delusions, may cause significant anxiety (Hanssen *et al.*, 2005) and additionally lead to involuntary hospital admission, highlighted by numerous studies to be a traumatic experience (Gorrell *et al.*, 2004; Quirk and Lelliott, 2001). As the onset of psychosis typically occurs during late adolescence, such experiences may also have a significant impact on an individual's sense of self / confidence, social networks, transition to autonomy and it also may significantly disrupt their plans for the future (MacDonald *et al.*, 2005; Sanbrook *et al.*, 2003).

In general, there is limited public understanding of mental health difficulties thus stigma and discrimination is common (Phelan *et al.*, 1998). In fact, a representative survey of the general population (n=5025) found that, typically, people with schizophrenia were perceived to be unpredictable and dangerous (Angermeyer and Matschinger, 2004). Research findings demonstrate that the stigma of mental health difficulties and specific features of psychosis (e.g. delusions) may lead to peers withdrawing (Mackrell and Lavender, 2004) and also, to the individual withdrawing from their peer group (MacDonald *et al.*, 2005). Over time, such social isolation may lead to individuals experiencing a sense of loss, hopelessness and depression (Kilkku *et al.*, 2003; MacDonald *et al.*, 2005; Power *et al.*, 2003).

First episode psychosis is typically associated with risk taking behaviours. Some findings indicate that adolescents experiencing psychosis are 'twice as likely to be sexually active, have intercourse without protection and use intravenous drugs' (Shield *et al.*, 2005, p.150). Psychosis is also associated with increased substance misuse, particularly cannabis (Lambert *et al.*, 2005) and tobacco (Wade *et al.*, 2006). However, the most significant risk to the individual with psychosis is suicide. Results from a meta-analysis into the lifetime risk of suicide in schizophrenia indicate rates of approximately 5% (Palmer *et al.*, 2005). A more recent retrospective inception cohort study of 2723 patients presenting with FEP explored the long term risk of suicide after a first episode of psychosis and found that there was a significant increase in risk in suicide compared with the general population (Dutta *et al.*, 2010). The authors demonstrated that suicide rates were highest in the first year after

presentation, occurred approximately 12 times more than expected based on rates from the general population, and that, even after a decade, this risk remained at a high level. Whilst this study does provide clinically relevant information regarding the increased risk of suicide after FEP, there are also limitations, given the relatively small sample size.

1.3.6 Impact of Psychosis and Caregiving on the Carer

Definition of a 'Carer'

This section refers to the family and friends who provide unpaid care to an individual with psychosis. Indeed, as contemporary mental health services encourage community care, carers of individuals with psychosis are typically members of the family, and predominantly parents or partners (Lauber *et al.*, 2003; Rethink, 2003). Whilst there are ongoing issues about the definition of a 'carer', for the purposes of this research the definition utilised is that provided by the Department of Health (DoH, 2001b). This states that carers include:

...all people over the age of 16 who care or intend to care for a person except paid carers and/or volunteer workers ... the carer does not have to be a relative or living with the person they care for (DoH, 2001b, p. 25).

Effect of Psychosis and Caregiving on Families / Carers'

Psychosis may also have a significant impact on those caring for the individual, particularly in FEP (Addington *et al.*, 2003). The term 'burden of care' has been adopted to identify the objective (e.g. practical problems such as disruption of family relationships and financial difficulties) and subjective difficulties (e.g. psychological reactions such as sadness, grief and a sense of loss) experienced by carers of individuals with mental health problems (Hoenig and Hamilton, 1966).

1.3.6.1 Objective Difficulties

Evidence suggests that the role of caregiving to a family member with mental health difficulties is often associated with permanent disruption to family relationships (Ryan, 1993), constraints to family life (Reinhard, 1994), financial disadvantage (Idstad *et al.*, 2010), and physical health difficulties (Pinquart and Sorensen, 2007).

1.3.6.2 Subjective Difficulties

With regard to subjective difficulties, it appears that providing care for an individual experiencing a mental health problem(s) is often associated with a complex myriad of feelings and emotions. These include increased stress when coping with challenging behaviour (Roick *et al.*, 2007), anxiety (Jeppensen *et al.*, 2005), depression (Gallant and Connell, 1997), and fears about the future (Barker *et al.*, 2001). Because of such emotions, carers may often feel overwhelmed and hopeless (Shore, 2006). Carers may also experience feelings of guilt resulting from the potential biological origins of the illness or for not having identified the symptoms earlier (Sanbrook and Harris, 2003). Other studies indicate that carers report a sense of grief and loss, attributable either to the loss of aspirations for the future of the person (with psychosis) (Patterson *et al.*, 2005; Tuck *et al.*, 1997) and/or the loss of the carer's former lifestyle (Magliano *et al.*, 2005a). In addition, stigma may also affect the carers of people with mental illness (Ostman and Kjellin, 2002). Several studies have demonstrated caregivers' experience of being avoided by friends and relatives during the family member's illness, leading to decreased self esteem and isolation (Schulze and Angermeyer, 2003). Indeed, a qualitative study of first time caregivers to people with FEP indicated that numerous carers, because of fears of stigmatization were secretive about the illness (McCann *et al.*, 2011).

However, there are a number of methodological limitations within this evidence base including the inconsistent use of theoretical and operational definitions, lack of longitudinal research and lack of control over other variables which may potentially influence burden. Indeed, it is likely that a number of factors may contribute or mediate the caregivers' perception of the burden of care, such as the age of caregivers (Baronet, 1999), level of expressed emotion in the family (Raune *et al.*, 2004), ethnicity (Rosenfarb *et al.*, 2006), symptom severity (Woltraus *et al.*, 2002), social support (Shah *et al.*, 2010) and mental health service intervention (Pilling *et al.*, 2002).

Furthermore, over the past decade, research has increasingly begun to focus on the positive impact of caregiving (Schulz and Sherwood, 2008). Some evidence suggests this may include feelings of satisfaction (Veltman *et al.*, 2002), increased self esteem (Chen and Greenberg, 2004) and an enhanced relationship with the care receiver (McCann *et al.*, 2011).

1.3.7 SUMMARY

In summary, it is clear that our understanding of psychosis, its aetiology and course remains incomplete, with many areas still hotly contested. However, what *is* apparent from the existing literature is the significant deleterious impact psychosis may have on the individual and their carer.

1.4. EARLY INTERVENTION FOR PSYCHOSIS SERVICES

1.4.1 Early Intervention for Psychosis Service Definition

Early intervention for psychosis services focus on the care of individuals in the prodromal and early phase of a psychotic disorder (National Institute for Clinical Excellence (NICE), 2010). The service is typically provided by a multi-disciplinary team (MDT) or a specialised section within a team (SCMH, 2003).

In the UK, EISs are directed towards the:

...early provision of effective age and phase-specific pharmacological and psychosocial interventions intended to minimise the severity of the initial psychotic episode, facilitate as full a recovery in an individual as possible to improve their quality of life, and minimise the human and social costs associated with psychosis (SCMH, 2003, p.18).

The aim of EIS is to ‘reduce the duration of untreated psychosis (DUP) to a service median of less than three months ... and provide support for the first three years’ (DoH, 2002, p. 54).

Whilst the term ‘early intervention’ may refer to either *primary intervention* at the prodromal stage (Gross and Huber, 1998), or *secondary intervention* at the acute phase (Edwards and McGorry, 2002), EISs within the United Kingdom (UK) typically provide secondary intervention (Pelosi and Birchwood, 2003).

1.4.2 Historical Context for the Development of Early Intervention for Psychosis Services

Traditionally, individuals experiencing psychosis were treated in long stay psychiatric in-patient units (Rogers and Pilgrim, 2001). However, pharmacological advances in treating psychosis and increasing costs led to movements towards de-institutionalisation, community

care and the management of this client group by multi-disciplinary community mental health teams (CHMTs) (Rogers and Pilgrim, 2001).

However, in the 1990's, emerging evidence began to support the case for the development of specialised EISs. This included Wyatt's seminal paper on the prognostic influence of DUP on outcome (Wyatt, 1991), the possible existence of a 'critical period' (Harrison *et al.*, 2001) and an association between longer DUP and poorer outcomes (Marshall *et al.*, 2005). Additionally, key research findings from the Early Psychosis Prevention and Intervention Centre (EPPIC) in Australia demonstrated the effectiveness of this service with respect to cost and outcomes for EPPIC patients (e.g. reduced positive symptomatology, improved quality of life) which were better at both 12 months and at 7-8 years follow up in comparison to the control group (McGorry *et al.*, 1996). The findings of this study are regarded as the precursor for the development of EISs (Singh, 2010).

In addition, it was increasingly becoming apparent that CMHTs had limited success in treating psychosis, with high drop-out (Robinson *et al.*, 1999) and relapse rates (Craig *et al.*, 2004) and concerns over managing risk (Ritchie *et al.*, 1994). Furthermore, evidence also suggested that clients were dissatisfied with the available services (Hagan and Nixon, 2011; Leese *et al.*, 1998; Parkman *et al.*, 1997; Tyson *et al.*, 2001) and the delays in accessing care (Rethink, 2003). This resulted in users' requests for services which improved their social and functional ability, offered psychosocial/psychological interventions, promoted independence (rather than fostering dependency), were person centred and collaborative (Noble *et al.*, 1999; Schrank and Slade, 2007) and offered home treatment (Piat *et al.*, 2008).

Such negative experiences of CMHT care were also reiterated by the carers of individuals with psychosis (Henwood, 1998; Hogman and Pearson, 1995; Leavey *et al.*, 1997; Pinfold *et al.*, 2004; Shepherd *et al.*, 1994; Tyson *et al.*, 2001), who expressed a desire for greater emotional and practical support, more information, education and training and specific psychotherapeutic interventions/pathways into employment for their relatives (Sin *et al.*, 2007).

Increasingly, research also began to indicate the utility of psychosocial therapies in treating psychosis (Chen, 1999; Gilbert *et al.*, 2003), such as family interventions (Tarrier and Bobes, 2000) and cognitive behavioural strategies (Gilbert *et al.*, 2003, Kuipers *et al.*, 1997; Lewis *et*

al., 2002; Sensky *et al.*, 2000). This was a significant finding given the high rates of discontinuation from neuroleptic treatment (Kane and Marder, 2005).

1.4.3 Early Intervention for Psychosis Service Policy

In 1998, EISs for young people with FEP were identified as part of the new structure of services for those experiencing severe mental health difficulties ‘to prevent relapse, reduce the risk of suicide and ensure public safety’ (DoH, 1998, p.55). In 1999, the National Service Framework for Mental Health (NSFMH) (DoH, 1999) emphasised the importance of early assessment of needs at the first indication of a psychotic illness in view of the ‘growing evidence that early assessment and treatment can reduce levels of morbidity’ (DoH, 1999, p.44).

Thus, EISs’ development was made a national priority for the first time in the NHS Plan (DoH, 2000). This plan stipulated that fifty EISs, for people with FEP, should be established across England by 2004, and provide treatment and active support in the community to young people and their families and that staff would carry caseloads of no more than 15 clients (in comparison to average caseloads of 35 in CMHT care (DoH, 2002a). It was envisaged that this would reduce the length of time people would remain untreated, promote recovery during the early phases of the illness and benefit approximately 7, 500 young people each year.

Detailed guidance regarding EIS provision was provided in the Mental Health Policy Implementation Guide (MHPIG) (DoH, 2001). This, alongside NICE guidelines for the treatment and management of schizophrenia (NICE, 2002; NICE, 2010), stipulated that EISs should provide care for: a) people aged between 14-35 years with a first presentation of psychotic symptoms; and b) people aged between 14-35 years during the first three years of psychotic illness. The MHPIG (DoH, 2001) also identified a number of key components for the service. These included:

...reducing stigma and raising awareness of symptoms of psychosis to reduce the duration of untreated illness; developing engagement; providing evidence-based treatments and promoting recovery for young people who have experienced an episode of psychosis; and working across the traditional divide between child and adolescent services and adult services, as well as in partnership with primary care, education, social services, youth and other services (NICE, 2010, p. 75).

In addition, the MHPIG (DoH, 2001) also emphasised the importance of treatment being offered in the least restrictive setting possible, collaboration with the client regarding treatment goals (e.g. regarding medication), family/carer involvement and providing a pathway to valued education and occupation.

In Wales, the development of EISs' provision came slightly later, although the Mental Health National Service Framework, too, recommended that EISs should to be accessible for each Trust (Welsh Assembly Government (WAG), 2005).

1.4.4 Essential Components of an Early Intervention for Psychosis Service

As the number of EISs began to increase, it was noted that there was a lack of clarity over the core structural and functional elements of an EIS. A study by Marshall *et al* (2004) sought to ascertain the essential elements of an EIS. This involved accessing the views of 21 UK health care clinicians in a Delphi exercise which used published guidelines (DoH, 2000) to develop a list incorporating 151 elements from 10 categories of team structure and function. The findings indicated that there was consensus between the professionals on 90% of the elements. Table 1 represents a summary of the recommendations for the essential principles of the EIS approach taken from the aforementioned study (Marshall *et al.*, 2004), the MHPIG (DoH, 2001), and McGorry (1997) provided in the Sainsbury Centre for Mental Health Guidance on developing an EIS (SCMH, 2003).

Table 1.1: Essential Elements of an Early Intervention for Psychosis Service (SCMH, 2003, p.29)

'Core Feature	Service design notes
Early detection and assessment	<ul style="list-style-type: none"> • It requires a strategy for detecting psychosis at the earliest possible stage, thereby minimising the DUP • Assessment needs to be comprehensive, involving all professional groups, clients, family and friends • Working with diagnostic uncertainty must be possible during the assessment phase
Pharmacological treatments	<ul style="list-style-type: none"> • Management of symptoms should include low-dose atypical neuroleptic medication, prescribed in accordance with NICE guidelines • There should be monitoring for side effects and prompt action taken to alleviate unwanted effects of treatment

	<ul style="list-style-type: none"> • Strategies for treatment resistance are required
Care coordination	<ul style="list-style-type: none"> • Key workers must be allocated rapidly and where necessary adopt assertive engagement strategies • Care plans need to be focused on recovery, with an emphasis on empowering the client • Planning must reflect the preferences and priorities of individual clients • All relevant parties (involving carers and significant others) should be involved in care planning • Sustained involvement should continue for three years • Caseloads for individual key workers should not exceed 15
Co-morbidity	<ul style="list-style-type: none"> • There needs to be specific and ongoing assessment and planning for: <ul style="list-style-type: none"> ○ Anxiety disorders ○ Depression ○ Suicidality ○ Alcohol/substance misuse ○ Post-traumatic features • Carer morbidity must also be recognised and assessed for
Basics	<ul style="list-style-type: none"> • Proper attention must be given to <ul style="list-style-type: none"> ○ Housing ○ Income/finance ○ Physical health care ○ Practical support
Psycho-social interventions	<ul style="list-style-type: none"> • Young people's personal and social development needs must be recognised and addressed • Psycho-education should be provided to clients', families and carers • Families should receive support and training around issues such as loss and adjustment, relapse prevention, expressed emotion, etc • Strategies for preventing relapse are required • Cognitive behavioural therapy should be available
Education and occupation	<ul style="list-style-type: none"> • All clients should undertake vocational assessment • Clients need to be supported into employment, education or other valued occupations, within normal environments • The achievement of normal social roles should be afforded the

	highest priority
Acute care	<ul style="list-style-type: none"> • Wherever possible, alternatives to hospital admission (e.g. home) for acute and crisis care should be found • Where needs indicate a period of care away from home, this should be provided in suitable, age appropriate environments, which are not necessarily restrictive • The use of the Mental Health Act should be avoided where possible
Style	<ul style="list-style-type: none"> • Embracing and promoting optimism about recovery is an essential cultural principle for the service • The service must be sensitive to individual needs relating to culture, age, gender etc • The service must be accessible, acceptable and engaging and particularly sensitive to the needs of young people
Partnerships	<ul style="list-style-type: none"> • The service needs to be designed and delivered using a partnership approach involving: <ul style="list-style-type: none"> ○ Primary care ○ Adult mental health services ○ Child and adolescent psychiatry ○ Social services ○ Non-statutory services ○ Education ○ Clients and carers ○ Youth organisations ○ Drug and alcohol services ○ Criminal justice services’.

However, an audit of EISs in England in 2005 revealed that out of 117 teams only three teams fully met the fidelity requirements of an EIS (Pinfold and Smith, 2007). Thus, there appears to be significant variations in EIS models and delivery across the country.

1.4.4.1 Recovery Orientated Service Approach

Definition of Recovery

Traditionally, it was believed that recovery from severe mental health difficulties was not possible (McGlashan, 1988). However, more recently it has been shown that

recovery from psychosis and schizophrenia is common (Davidson and McGlashan, 1997). Reflective of this shift, recovery is increasingly being integrated within Department of Health policies in the UK (DoH, 2000; DoH, 2001; DoH, 2006a, DoH, 2007a; Health and Social Care Act, 2001) and underpins EIS's philosophy and practice (Repper and Perkins, 2003).

The definition of 'recovery' is contested (Pilgrim, 2008a; Ramon *et al.*, 2007). Nevertheless, a widely used term posits that recovery is:

A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993, p. 527).

However, there is greater consensus on the key components of the recovery process. These are described below in Table 1.2.

Table 1.2: Key Components to the Process of Recovery (Andresen *et al.*, 2003, cited in Shepherd *et al.*, 2008, p. 2)

Components of the process of recovery	
Finding and maintaining hope	Believing in oneself; having a sense of personal agency; optimism about the future;
Re-establishment of a positive identity	Finding a new identity which incorporates illness, but retains a core, positive sense of self;
Building a meaningful life	Making sense of illness; finding a meaning in life, despite illness; engaged in life;
Taking responsibility and control	Feeling in control of illness and in control of life.

Thus, increasingly, the emphasis within recovery orientated services (which goes beyond the previous psychiatric service definition of recovery involving the cessation of symptoms is to:

... help patients back into mainstream society, re-defining recovery to incorporate quality of life - a job, a decent place to live, friends and a social life" (Appleby, 2007a, p. 3).

Such an emphasis echoes a plethora of research with regards to consumers' views of what factors are key to the recovery process, such as, social support (Hendryx *et al.*, 2009), a safe place to live (e.g. not temporary housing) (Davies *et al.*, 2009) and meaningful occupational roles (which impact positively on individuals sense of self and daily structure) (Andresen *et al.*, 2003; Spandler *et al.*, 2007). Further research has also highlighted the importance of *internal* factors, such as determination and a positive mental attitude in recovery from mental illness (Ralph, 2000).

Whilst the literature indicates that the 'recovery journey' is different for each individual (Shepherd *et al.*, 2008), evidence suggests that there might be a multitude of factors which may either help (e.g. supportive relationships) or hinder (e.g. coercive treatment, severity of symptoms, involvement with indifferent professionals) this process (Kelly and Gamble, 2005; Mancini *et al.*, 2005). However, there appear to be five stages within the recovery process that are broadly applicable. These are illustrated below in Table 1.2.

Table 1.3: The Five Stages of Recovery (Andresen *et al.*, 2006, cited in Shepherd *et al.*, 2008, p.4)

Stage of recovery	
Moratorium	A time of withdrawal characterised by a profound sense of loss and hopelessness;
Awareness	Realisation that all is not lost and a fulfilling life is possible;
Preparation	Taking stock of strengths and weaknesses regarding recovery and starting to work on developing recovery skills;
Rebuilding	Actively working towards a positive identity, setting meaningful goals and taking control of one's life;
Growth	Living a meaningful life, characterised by self-management of the illness, resilience and a positive sense of self.

The Role of Professionals in Mental Health Services

Despite changes in service delivery, many individuals are often reluctant to engage with mental health services (SCMH, 1998). This may be due to the nature of their symptoms, their past negative experiences of mental health care services, aversion to the treatments available (e.g. medication), and a myriad of challenging emotions associated with receiving support from psychiatric services (e.g. stigma) (Davidson and Roe, 2007; SCMH, 1998). Thus, professionals are *key* to the process of engaging the individual in services (Shepherd *et al.*, 2008).

Specifically, evidence suggests that there are a number of particular personal characteristics of professionals which may contribute to the development of a therapeutic alliance and subsequent engagement with services (Ackerman and Hilsenroth, 2003; Davies *et al.*, 2009). Literature indicates that these attributes and/or traits include warmth and openness (Borg and Kristiansen, 2004; Mohl *et al.*, 1991), trustworthiness (Hovarth and Greenberg, 1989), and being caring (Borg and Kristiansen, 2004).

In addition, there is also evidence to suggest that there may be particular staff approaches which are useful in the process of engagement when working with consumers of mental health services (Davies *et al.*, 2009). These include ‘going the extra mile’ (Borg and Kristiansen, 2004), normalising (Rethink, 2009), giving hope (Deegan, 1996; Perkins, 2006), listening, understanding and treating the person as an individual who has the capability to make decisions regarding their treatment (Shepherd *et al.*, 2008). Thus, increasingly, there is a drive to place consumers’ personal preferences at the centre of the process e.g. person centred planning (DoH, 2010). Indeed, evidence suggests that consumers’ who feel that their wishes and/or their experiences are not being listened to / judged are likely to disengage from services (Davies *et al.*, 2009).

Furthermore, the recovery approach also necessitates a different relationship between client’s and mental health professionals. Typically, it is found that this takes the form of mentorship or guiding (Davies *et al.*, 2009), with individuals directing the pace of their own recovery (Shepherd *et al.*, 2008) and professionals offering ‘their professional skills and knowledge whilst learning from and valuing the patient, who is an expert by experience’ (Roberts and Wolfson, 2004, p. 38). Therefore, the objectives of the mental health professionals in such services are to provide services which are ‘on tap’, rather than ‘on top’ (Repper and Perkins,

2003) and equip the individual with information, skills, networks and opportunities for meaningful occupation and empower the individual to make decisions for themselves (Rethink, 2009; Shepherd *et al.*, 2008).

Furthermore, it is also important that mental health professionals facilitate the recovery of the carers and/or families of those experiencing mental health difficulties. This is crucial, given the evidence which demonstrates the potentially devastating impact of a family member's mental health problems on these individuals (Shepherd *et al.*, 2008) and the vital role of the family in the persons recovery from FEP (Addington, 2007; Pharoah *et al.*, 2010).

1.4.5 Effectiveness of Early Intervention for Psychosis Services

The early intervention paradigm can be sub-divided into two sections for the evaluation of effectiveness. The first section incorporates the identification of those at risk and preventative interventions undertaken prior to the onset of psychosis. The second section is after onset of psychosis and characterised by early initiation of treatment (i.e. minimising DUP). These will be discussed in turn.

1.4.5.1 Effectiveness of Early Intervention Prior to the Onset of Psychosis

Identification of Individuals at Risk from Developing Psychosis

Identification of individuals who may be at risk from developing psychosis is the key component of pre-onset intervention (Killackey and Yung, 2007). However, this process may be difficult (Hambrecht *et al.*, 2002) and screening methods, such as the 'Ultra High Risk' criteria (Yung *et al.*, 2004) developed to identify people at risk of developing psychosis, have been criticised, primarily because of the high false-positive rate (Warner, 2005). Therefore, the clinical staging model, which recommends the provision of less invasive interventions (e.g. psycho-education as opposed to medication) in cases of early identification, is increasingly being adopted (McGorry *et al.*, 2006).

Interventions in the Pre-Psychotic Phase

Interventions in the pre-onset phase are aimed primarily at preventing transition to psychosis and treating existing problems such as co-morbid depression (Killackey and Yung, 2007). Typically, pharmacotherapy (e.g. neuroleptic or anti-anxiolytic medication) and/or psychotherapy (e.g. cognitive behavioural therapy (CBT)), targeted at positive symptoms

and/or co-morbid syndromes are offered to individuals in the pre-onset stage (Ruhrmann *et al.*, 2005). The evidence base for the effectiveness of these early intervention strategies is relatively limited. However, a randomised controlled trial (RCT) of interventions designed to reduce the risk of progression to FEP comparing a needs-based intervention (NBI) (e.g. supportive psychotherapy and case management) with a specific preventative intervention (SPI) (e.g. a low dose of neuroleptic medication and CBT) indicated that SPI reduces the risk of early transition to psychosis in young people at high risk, finding a reduction in the progression to psychosis at the end of treatment, although not at 6 months follow up (McGorry *et al.*, 2002).

Whilst the findings offered useful information on the delay of onset, there were limitations to the study, such as a lack of blinding and uncertainty regarding the relative contributions of pharmacotherapy and CBT. Further research exploring these components in greater depth revealed mixed findings. A RCT exploring cognitive therapy in the prevention of psychosis in people at ultra high risk indicated it to be an efficacious intervention in reducing the likelihood of progression to psychosis (Morrison *et al.*, 2007). However, a randomised, double blind trial of Olanzapine (neuroleptic medication) versus a placebo in patients with prodromal symptoms found a non-significant difference (McGlashan *et al.*, 2006). A Cochrane review of early intervention in psychosis also found inconclusive evidence to suggest that that people in the prodromal phase could be helped by interventions (Marshall and Rathbone, 2011). Thus, it appears from the limited research available that the benefits of prodromal intervention have not been unequivocally demonstrated, although presently it seems that psychological or psychosocial components alone, or in addition to medication, may potentially be more effective than medication alone.

However, ‘very early’ interventions are controversial and have attracted criticism, such as, the risk of people being ‘mislabelled, potentially stigmatised and exposed to treatments that they did not need because they were not going to develop psychosis’ (Killacky and Yung, 2007, p. 122). Therefore, it is clear that further research is required within this area to refine predictive tools and to clarify *which* interventions are required at *what* stage.

1.4.5.2 Effectiveness of Early Intervention Post-Onset of Psychosis

In order to examine the effectiveness of early intervention post the onset of psychosis, the evidence may be further sub-divided into three key areas. These include: 1) clarification over whether the DUP is related to poorer outcomes, (as reducing the DUP is a key target of EIS); 2) examining whether EIS can reduce the DUP, and; 3) identifying whether EISs bring about positive outcomes with regard to symptoms and level of functioning (Killackey and Yung, 2007).

Duration of Untreated Psychosis and Outcome

There is some debate within the literature about whether DUP is related to outcome. Some studies have found no association between DUP and clinical outcome (Craig, 2000; de Haan *et al.*, 2000; Ho *et al.*, 2000), whilst others have noted that longer DUP is associated with worse outcomes (McGorry, 2000; Ross *et al.*, 2005). More recently, a systematic review and meta-analysis of follow-up studies of FEP cohorts indicated an association between DUP and poorer outcome (Marshall *et al.*, 2005). There was a significant association between DUP and a broad range of outcomes (e.g. positive symptoms, negative symptoms, social functioning) at six and twelve months follow up. Furthermore, individuals with long versus short DUP were significantly less likely to achieve remission. Thus, this study appears to demonstrate evidence for a modest association between DUP and several outcomes. Similar findings were also reported in a further critical review and meta-analysis examining the relationship between DUP and outcome in first episode schizophrenia (Perkins *et al.*, 2005). However, many of the studies included in both meta-analyses did not involve blinding of the researchers to participants' DUP status, and did not control for a third factor - pre-morbid adjustment. Additionally, it is notable that the presence of an association between DUP and poorer outcome does not necessarily indicate a causal link.

Overall, and while there are clearly limitations to the existing evidence base regarding the association between DUP and outcome, such as the difficulty in establishing a precise definition of the DUP (Norman and Malla, 2001), a lack of confounding for other variables which may impact on outcomes, such as adherence to medication (Verdoux *et al.*, 2000) or substance misuse (Linszen *et al.*, 1994), in general evidence does appear to indicate that DUP is related to poorer outcomes (Killackey and Yung, 2007)

Effectiveness of Interventions Reducing Duration of Untreated Psychosis

It was unknown whether reducing DUP would improve outcomes and/or whether EIS's would be an effective method to reduce DUP. Thus, the early Treatment and Intervention in Psychosis study (TIPS), utilising a non-randomised quasi experimental method, investigated whether a specialised early psychosis detection programme and community awareness campaign for people presenting with FEP could reduce DUP and improve outcomes, in comparison to two parallel health care areas without the early detection programme (Larsen *et al.*, 2007). The findings indicated that DUP was significantly shorter for those in the early detection area compared to those from the non-detection areas (5 weeks versus 16 weeks, $P=0.0003$). Symptom levels in those from the early detection area were significantly lower (e.g. better outcomes on the *Positive and Negative Syndrome Scale (PANSS)* (Kay *et al.*, 1987) and *Global Assessment of Functioning (GAF)* (Endicott *et al.*, 1976)), both at baseline and 3-month follow-up (Melle *et al.*, 2004). In addition, rates of suicidality in those from early detection areas were also lower (Melle *et al.*, 2006). However, there were no differences in subjective quality of life between the two areas attributable to reduction in DUP, although the authors suggested that 'functional deterioration preceded symptom onset' (Melle *et al.*, 2005, p. 336). At one year follow up, Larsen *et al* (2006) indicated that there was no difference between groups for the course of psychosis over the first years, and no variation in functional outcome or positive and general symptoms. However, the early detection group had significantly lower levels of negative symptoms and better peer networks (Larsen *et al.*, 2007), which were maintained at two years follow up (Melle *et al.*, 2008).

Whilst this research indicated that early psychosis detection and intervention can be effective in reducing DUP, there are limitations to the study. These include non-random allocation to groups, lack of accounting for other factors which may affect outcome, and the risk that the patient populations may be incomparable. It is also clear that a RCT would be the most effective design to study this phenomenon, although it is accepted that there would clearly be ethical issues with such a design.

Effectiveness of Interventions for the First Episode of Psychosis

There appears to have been two studies that have utilised a randomised controlled study design to evaluate the effectiveness of outcomes of FEP services. The first was the OPUS study in Denmark, which used an RCT to compare the effects of integrated treatment

(assertive community treatment including family therapy and social skills training) with standard treatment (contact with a community mental health centre) and included 547 patients aged 18-45 diagnosed with schizophrenia spectrum disorders (Thorup *et al.*, 2005). Treatment was provided for two years, with follow-ups at one and two years, and outcomes such as symptoms, substance misuse, *GAF* rating, accommodation and employment were measured. The results from the study indicated that the integrated treatment had advantages over the standard treatment across all areas of outcome at one and two years follow up (Peterson *et al.*, 2005). In addition, findings also indicated that the relatives in the integrated treatment felt significantly less burdened by caregiving and were more satisfied with treatment (Jeppesen *et al.*, 2005). Whilst these results offered support for the effectiveness of early intervention regarding symptom reduction and increased levels of functioning, it is notable that outcome measures did not appear to be blinded and there was a high attrition rate which may have biased outcomes. In addition, improvements in the *PANSS*, global functioning and substance use did not appear to be maintained at five-year follow up, although participants from OPUS integrated treatment had a reduced use of hospital admissions in comparison to those from the standard treatment (Bertelson *et al.*, 2008).

The second trial was the Lambeth Early Onset (LEO) study which used a RCT to investigate the effectiveness of specialised care for early psychosis (Craig *et al.*, 2004). A total of 144 people aged 16-40 years presenting to mental health services with non-organic or affective psychosis were randomised to either standard treatment (CMHT care) or a specialised EIS over a 19 month period. The results indicated that those receiving specialist treatment were re-admitted on fewer occasions and had a reduced drop-out rate from services. Further analysis of this study indicated that those participants treated by the specialised team were more compliant with medication, more engaged in vocational activity and were more effective in establishing social relationships than the control group at 18 months follow up (Garety *et al.*, 2006). Whilst this research adds to the evidence base on the effectiveness of specialised EISs, there are some study limitations, such as, the small under-powered sample size and reliance on hospital records for data on relapse. Furthermore, critics have also suggested that the results are not attributable to the specialist service *per se*, but rather to the comparison with an inadequately resourced standard service (Garety and Rigg, 2001). In addition, a similar study found no significant differences on measures of psychopathology, quality of life and overall functioning (Kuipers *et al.*, 2004), whilst another indicated that at

five year follow up any reductions in hospital admissions had ceased (Gafoor *et al.*, 2008). Hence, there are some questions over whether ‘the short term benefits of early intervention programmes are translating into longer term gains’ (Bosanac *et al.*, 2010, p. 10), and for what time period early intervention should continue (Linszen *et al.*, 2001).

Nevertheless, other studies have also indicated the effectiveness of EISs in improving symptoms and functional outcome (Addington *et al.*, 2003; Culberg *et al.*, 2002), reducing hospital admissions (Dodgson *et al.*, 2008), reducing relapse rates (Addington, 2007), reducing suicide rate (Harris *et al.*, 2008) and reducing costs to health care (Culberg *et al.*, 2006). A recent Cochrane review of the effectiveness of early intervention for psychosis has indicated that there is some support for specialised EISs, although further trials are necessary to establish whether the gains achieved are sustained (Marshall and Rathbone, 2011). However, the impact of EI on occupational functioning appears minimal and potentially this may be attributable to external factors, such as stigma (Malla and Payne, 2005).

However, as identified in section 1.4.4, early intervention incorporates a number of treatment components (Catts *et al.*, 2010). Indeed, the majority of studies described have utilised multi-faceted interventions involving CBT, family intervention and pharmacological approaches, with limited opportunity to dis-aggregate the components. Hence, it is unclear which, if any, may be the ‘active’ ingredients (Catts *et al.*, 2010). However, there is some evidence available regarding the effectiveness of these separate elements in the treatment of FEP. These will be discussed briefly in turn.

Family Intervention

Families are considered to play a vital role in the person’s recovery from FEP (Addington, 2007). Whilst one literature review of family intervention (FI), involving psycho-education, problem solving and stress reduction techniques in FEP indicated that there is limited and conflicting evidence regarding the effectiveness and efficacy of family intervention for this population (Askey *et al.*, 2007), other research indicates more encouraging findings. Specifically, literature indicates the effectiveness of FI with regard to reduced relapse (Addington *et al.*, 2005; Linszen *et al.*, 1996; Pharoah *et al.*, 2010), improved functioning for the client (Tarrier and Bobes, 2000), and reductions in burden, improved quality of life and satisfaction for carers (Tarrier and Bobes, 2000) particularly with high expressed emotions families (Raune *et al.*, 2004). More recently, a systematic review assessing FI in early

psychosis indicated that those receiving FI were less likely to relapse or to be admitted to hospital than those receiving standard care (Bird *et al.*, 2010).

Cognitive Behavioural Therapy

Cognitive behavioural therapy, targeted at reducing the distress and disability associated with psychotic symptomatology, is widely advocated as an important intervention in the treatment of psychosis (Addington and Gleeson, 2005; Hermann-Doig *et al.*, 2003). Whilst an RCT of CBT in early schizophrenia indicated there were no significant differences between the impact of CBT or supportive therapy on symptoms, relapse rate or admission to hospital (Tarrier *et al.*, 2004), other studies provided more positive findings. These included a greater and more rapid reduction in symptoms in comparison to treatment as usual (Lewis *et al.*, 2002). A more recent systematic review of CBT in the treatment of psychosis also indicated that CBT has longer term benefits in reducing symptom severity and associated distress, although it does not appear to reduce relapse or admission rates (Bird *et al.*, 2010). However, whilst useful, the results of the systematic review should be approached with caution due to the paucity of trials included (n=4).

Pharmacological Interventions

Finally, whilst there is some evidence for the effectiveness and efficacy of neuroleptic medication in the treatment of psychosis (Kahn *et al.*, 2008; Robinson *et al.*, 2005), other studies suggest that their effectiveness is more limited (Lieberman *et al.*, 2005). It is suggested that this either may be as a result of discontinuation due to intolerable side effects e.g. tardive dyskinesia (Kane and Marder, 2005) or because research has yet failed to find that psychosis has any particular cause (Johnstone, 2000). However, what is clear is that much needs to be done methodologically within this evidence base to establish the effects of medication across a number of domains.

1.4.6 SUMMARY

Whilst there are some criticisms that EISs are led by ‘faith before facts’ (Bosanac *et al.*, 2010; Pelosi, 2009), and are disruptive to continuity of care (Yung, 2012), it is apparent that there is an increasing and persuasive body of evidence regarding the effectiveness and efficacy of EISs. Yet, it is clear that more research is needed to clarify how long early

intervention needs to continue, how any gains achieved may be maintained, and the impact of the separate components of an EIS.

1.5 SYSTEMATIC LITERATURE REVIEW

1.5.1 Systemic Literature Review of Clients' and Carers' Experiences of an EIS

In this section, an in-depth analysis of the relevant literature closely related to the current study will be provided. This review will also incorporate the process undertaken to search and review the evidence base.

1.5.2 METHOD

1.5.2.1 Search Strategy

The researcher conducted an electronic search using the ASSIA, British Nursing Index, EMBASE (1996-2012), MEDLINE (1996-2012), Web of Knowledge and PsycINFO databases. The search terms are presented in Appendix 1.

The database search was conducted in March 2011 and December 2011, and restricted to English language papers or papers with an abstract in English published after 1996. Additional articles were identified by searching tables of contents of relevant journals (see Appendix 2), reference lists of retrieved articles and using the ISI Web of Knowledge to locate all articles that had cited the included studies. The researcher also utilised resources such as Scirus, OpenSIGLE, PQDT to search for grey literature and regularly updated the literature search, with the final update in February 2012. However, it is notable that because several search strategies were completed, it is possible that duplicates occurred.

1.5.2.2 Selection of Relevant Studies

The researcher screened the titles and abstracts of all citations and retrieved the full text version of relevant articles to review for inclusion eligibility. The studies were included if they measured clients' and/or described carers' or families' views, experiences, or satisfaction with EISs. A cut off publication year of 1996 was utilised given that the concept of EISs, initially known as *Early Detection Services*, was developed in approximately 1996 (McGorry *et al.*, 1996). All studies meeting the eligibility criteria were assessed using the Critical Appraisal Skills Programme (CASP) (2001) tool for qualitative research.

1.5.2.3 Data Extraction and Synthesis

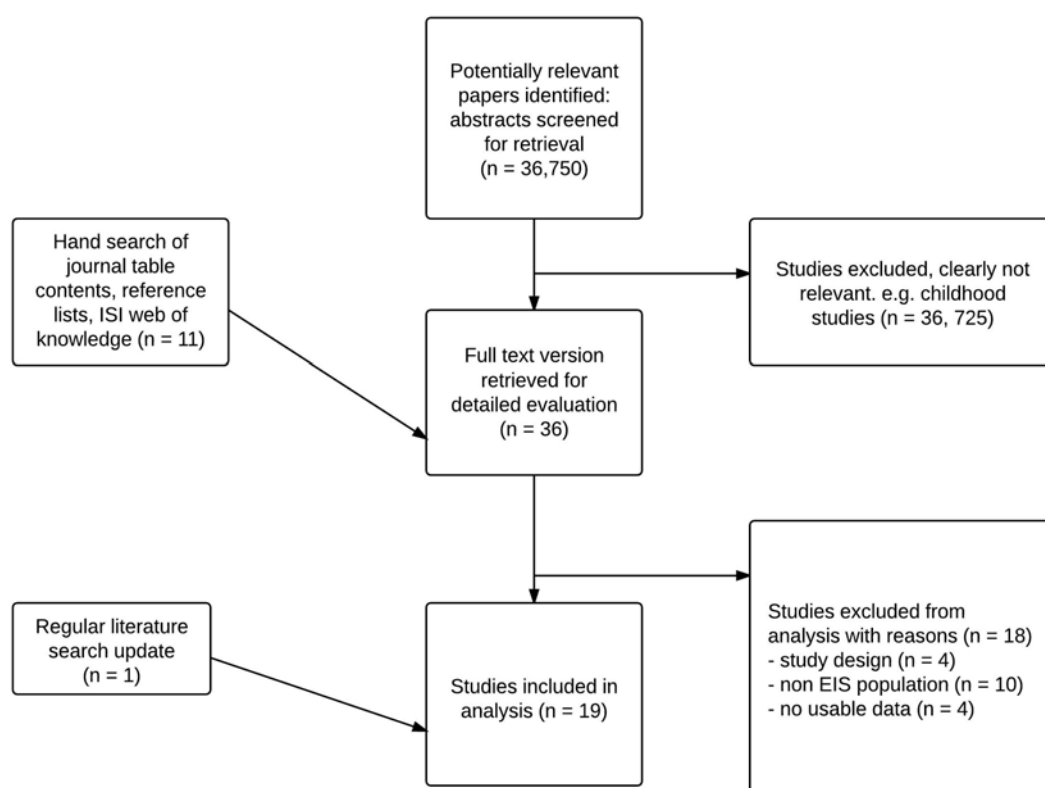
The researcher extracted data from all studies that met the inclusion criteria (see Appendix 3 for data extraction tool). Studies were sub-divided based on whether they referred to either: 1) clients', 2) carers' or, 3) clients' and carers' experiences of EISs.

1.5.3 RESULTS

The results of the search process and total number of articles included in the review are given in Figure 1. The database search retrieved 36, 750 studies of which 25 were initially considered relevant for the review. The manual search obtained 11 studies. Thus, in total 36 full text articles were identified. After detailed evaluation by the researcher, 18 studies were excluded because of: 1) study design e.g. for reasons identified in the CASP (2001) such as poorly applied and presented research approaches (n=4), 2) non-EIS population (n=10), and 3) no useable data (n=4). One additional study was located through a regular update of the literature search.

Therefore **19** studies met the inclusion criteria for this systematic review.

Figure 1: Flow Chart of Systematic Review Search Strategy and Study Inclusion



1.5.3.1 Study Characteristics

The characteristics of the included studies are summarized in Table 1.4. Studies were conducted in a variety of countries (n=6), although the majority of studies were conducted in the UK (n=11). All the studies were published in English. The sample sizes of clients and carers within studies varied substantially, ranging from 1-144. Approximately 50% of the studies utilised a qualitative study design (n=9). Other study designs involved mixed method or survey designs. Seven studies included only clients, whilst six included solely carers. Six studies included both clients and carers. The literature pertaining to clients' experiences of an EIS, carers' experiences of an EIS, and clients' and carers' experiences of an EIS will now be considered in turn. Studies will be presented in chronological order.

Table 1.4: Characteristics of Studies Included in the Review (n=19)

Key

(CL): Clients' only research

(CA): Carers' only research

(C&C): Clients' and Carers' research

Reference	Design and Objective	Number of participants	Age/gender	Diagnosis or other defining characteristics of the population	Measures employed	Key findings	Limitations (internal and external validity)
1. (C&C) Fisher and Savin-Baden (2001). The benefits to young people experiencing psychosis, and their families, of an early intervention programmes: evaluating a service from the consumers' and the providers' perspectives. British Journal of Occupational Therapy, 64, 58-64.	Service evaluation utilising interviews to investigate whether TIME (EIS) met the needs of its consumers and providers. Interviews were audio taped and analysed using IPA	5 TIME clients' 1 carer 7 professionals	Age/gender not reported	Client: Involvement with TIME and with a diagnosis of schizophrenia or related disorder – aged between 16-25 years Carer: Involvement with TIME through caring for a family member with FEP Professional: Involvement through developing or	n/a	Main findings indicated consumers experienced service as empowering, supportive and collaborative	Fidelity to EIS MHPiG (2001) limited-therefore questionable comparability with other EIS's Research limited to a single site Small sample size More realistic evaluation of programme through longitudinal study design

				implementing TIME			
2. (C&C) Stanbridge <i>et al.</i> , (2003). A study of families' satisfaction with a family interventions in psychosis service in Somerset. Journal of Family Therapy, 25, 181-204.	Mixed methods study design utilising semi-structured interviews and rating scales with families to investigate family satisfaction and clinical outcome. Interviews were audio-taped and analysed using thematic analysis	21 family members and 4 clients from 15 families	Age not reported 15 females, 10 males	Families referred to the family interventions in psychosis service. Criterion for referral - presence of psychotic symptoms in a family member	Rating scales for satisfaction	Key findings indicated initial apprehension/negative preconceptions about the service but high levels of engagement and satisfaction. Service had helped families deal with difficulties. Importance of positive therapeutic qualities (e.g. empathic, collaborative approach) highlighted	Fidelity to EIS MHPIG (2001) limited-therefore questionable comparability with other EIS's. Small client sample size Limited statistical analysis Reliability and validity of satisfaction scale not demonstrated.
3. (CL) O'Toole <i>et al.</i> , (2004). Treating first episode psychosis-the service users' perspective: a focus group evaluation. Journal of Psychiatric and Mental Health Nursing, 11, 319-326.	Qualitative study using focus groups to explore clients' experiences of an EIS. Focus groups with clients' audio-taped & analysed using IPA	12 EIS Clients	Age/gender not reported	Involvement with an EIS team and with a diagnosis of schizophrenia or schizoaffective disorder	n/a	Key findings indicated 'human approach' as key to recovery. Participants valued collaboration, flexibility, treatment at home, high nurse to client ratio and the provision of daily structure. EIS input led to a reduction in symptoms, increased confidence/independence	Self selecting sample therefore possible positive bias Challenges of focus groups e.g. capturing dominant group members' views Clients' views consistently positive-approach findings with caution

<p>4. (CL) Garety <i>et al.</i>, (2006). Specialised care for early psychosis: symptoms, social functioning and patient satisfaction. British Journal of Psychiatry, 188, 37-45.</p>	<p>Randomised controlled trial evaluating the effects of EIS on clients' clinical and social outcomes and satisfaction</p>	<p>144 Clients randomly allocated to EIS (n=71) or CMHT (n=73)</p>	<p>Clients aged between 16-40</p> <p>Average age – 26</p> <p>The 'majority of the sample were male' – 65%</p>	<p>All clients with first time non organic or affective psychosis</p>	<p><i>Positive and Negative Syndrome Scale (PANSS)</i> (Kay <i>et al.</i>, 1987)</p> <p><i>Global Assessment of Functioning (GAF)</i> (Endicott <i>et al.</i>, 1976)</p> <p><i>Calgary Depression Rating Scale</i> (Addington <i>et al.</i>, 1993)</p> <p><i>Scale for the assessment of insight</i> (David <i>et al.</i>, 1992)</p> <p><i>Verona satisfaction scale</i> (Ruggeri and Dall'Agnola, 1993)</p> <p><i>Manchester assessment of quality of life</i> (Priebe <i>et al.</i>, 1999)</p> <p>Housing/vocational/relationship status</p>	<p>Outcomes for EIS clients were significantly better at 18 months for social and vocational functioning, satisfaction and quality of life</p> <p>Significant effect favouring the EIS group, with differences attributable to the manner, competence and listening abilities of staff</p>	<p>Underpowered sample size</p> <p>Poor follow up rates(n=99)</p> <p>Researchers not blinded to treatment condition</p> <p>Concept of satisfaction complex-queries whether it is measurable by rating scale</p>
<p>5. (C&C) Birchwood <i>et al.</i>, (2006). EDEN: Evaluating the development and impact of early intervention services (EIS's) in the West Midlands: a report for the NHS service delivery and organisation national R & D programme. Retrieved 12 November 2011 from http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1304-042_V01.pdf</p>	<p>Multi-case study using case note data and interviews with clients, carers and professionals to evaluate the implementation and impact of EIS's. Interviews were audio-taped and recorded using constant comparative</p>	<p>32 clients, 18 carers, 42 health executives and 162 EIS professionals from 14 EIS's</p>	<p>Age/gender not reported</p>	<p>Client: Involvement with an EIS and with FEP</p> <p>Carer: Involvement with EIS through caring for a family member with FEP</p> <p>Professional:</p>	<p>n/a</p>	<p>Key findings regarding EIS development and delivery were that EIS sustained engagement (e.g. through accessibility and perseverance), clients had negative preconceived ideas (stigma) about treatment, but both clients and carers experienced the service as useful (e.g. staff</p>	<p>Data only from one geographical area in England</p> <p>Sampling method-via case manager may have recruited a sample with more positive views</p> <p>Carers sample consisted mainly</p>

	analysis			Involvement through developing or implementing an EIS		availability, positive therapeutic relationships)	of women (n=14)
6. (CL) Larsen (2007). Understanding a complex intervention: person centred ethnography in early psychosis. Journal of Mental Health, 16, 333-345.	Person centred ethnographic study of clients investigating 'the value of a social science perspective of interpretive understanding to study socio-cultural processes in a complex intervention' (EIS) (Larsen, 2007, p. 333). Study involved 2 years participant observation and repeated (6) interviews. 1998-2000	15 clients from a Danish EIS	Age/gender not reported.	Involved with EIS and diagnosed with a serious mental illness within the 'schizophrenic spectrum'	n/a	EIS helped clients' to develop a greater sense of self, understand of their difficulties and develop more realistic expectations for their futures. The quality of the relationship between clients and professionals was highlighted to be important.	Process of data analysis and researcher reflexivity not sufficiently reported Query over comparability of Danish EIS to UK EIS Criticisms of person centred ethnographic research design as too subjective and not rigorous.
7. (CA) Sin <i>et al.</i> , (2007). Developing services for carers of young adults with early-onset psychosis – implementing evidence-based practice on psycho-educational family intervention. Journal of Psychiatric and Mental Health Nursing, 14, 282-290.	Service evaluation, using a series of measures and a questionnaire to evaluate carers' experiences of an EIS family intervention	Number of carers not reported	Age/gender not reported	Carers involved with EIS through caring for a family member with FEP	<i>Knowledge on Schizophrenia Illness</i> (Barrowclough and Tarrier, 1995) <i>Carers' Assessment of Managing Index</i> (Nolan et al, 1995) <i>Experience of Caregiving Inventory</i> (Szmukler et al, 1996)	Only key findings from the semi-structured questionnaire reported: satisfaction with the group in general (e.g. instilling hope, support) and the group content (e.g. increased knowledge)	Full methodology (e.g. sample size, process of data analysis) and findings of the study not provided

8. (CL) Theuma <i>et al.</i> , (2007). Evaluation of a New Zealand early intervention service for psychosis. New Zealand Journal of Psychology, 36, 136-145.	Mixed methods design involving using the <i>PANSS</i> and <i>HoNOS</i> scores collected over 5 time period from intake -24 months and interviews with clients to assess the effectiveness of an EIS	100 EIS clients	60 between 15-35, 40 between 24-40 66 male, 34 female	Involvement with an EIS	<i>Positive and Negative Syndrome Scale (PANSS)</i> (Kay <i>et al.</i> , 1987) <i>Health of the Nation Outcome Scale (HoNOS)</i> (Wing <i>et al.</i> , 1998) Engagement and medication concordance rated via 5 point Likert scale by staff. Satisfaction questionnaires and clinical interviews.	Better outcomes were associated with length of contact with the service. Levels of satisfaction appeared high - possibly associated with a collaborative therapeutic relationship rather than the treatment modality.	Absence of a control group. Small numbers involved in the satisfaction surveys (n=13) and interviewed (n=4), therefore sample bias and generalisations not possible. Biased outcome measures as staff report. Absence of rigorous qualitative data analysis
9. (CL) Collishaw (2007). Clients' experiences of an early intervention service for psychosis. Unpublished dissertation.	Qualitative study using interviews and focus groups to explore clients' experiences of an EIS. Interviews audio-taped and analysed using GT	12 EIS clients	Mean age - 24 2 female, 10 male	EIS clients with a first episode symptoms of schizophrenia DSM- IV-TR (APA, 2000)	n/a	Key findings indicated overall positive experiences of the EIS across 3 areas: 1) engagement, 2) promoting recovery and 3) moving on.	Case manager may have recruited a sample with more positive views Not peer reviewed
10. (C&C) Naik and Bowden (2008). Early intervention in psychosis: client and carer perspectives. Nursing Times, 104 (18), 32-39.	Survey evaluating how clients and carers experience EIS in relation to best practice	21 EIS clients and 32 carers'	Age/gender not reported	Involvement with an EIS	Questionnaires for clients and carers based on EIS good practice guidance (DoH, 2001) and scored using 5-point Likert scales.	Key findings identified clients and carers perceived the EIS to meet best practice guidance. Areas where guidelines were adhered to closely were:	Limited pilot of questionnaire-no statistical tests of reliability Bias of a set

	guidelines					helpfulness of initial contact (carers), improved understanding/coping (clients) and satisfaction with frequency and context (clients and carers) of appointments	response type Self selection bias in sample Survey method produces data which lacks depth
11. (CA) Penny <i>et al.</i> , (2009). Whispering on the water: British Pakistani families' experiences of support from an early intervention service for first-episode psychosis. <i>Journal of Cross Cultural Psychology</i> , 40, 969-987.	Qualitative study involving semi-structured interviews with caregivers exploring experiences of support from an EIS. Interviews were audio-taped & analysed using Interpretative Phenomenological Analysis (IPA)	11 caregivers from 6 British Pakistani families	Age not reported 8 females, 3 males	Carers involved with EIS through caring for a family member with FEP	n/a	Three super-ordinate themes identified: Loss, 'a social illness' and 'divergent points on the path to change'	Communication difficulties: family interpreter may have altered responses Volunteer sample Social desirability in responding due to group interviews with families
12. (CL) Hardy <i>et al.</i> , (2009). Journey into and through an early detection of psychosis service: the subjective experience of persons at risk of developing psychosis. <i>Early Intervention in Psychiatry</i> , 3, 52-57.	Qualitative study using semi-structured interviews to explore experiences of persons at risk of developing psychosis. Semi-structured. Interviews audio-taped & analysed using Grounded Theory (GT)	10 EIS Clients	Age range between 16-30 years. Mean age- 21.8 years. 6 female, 4 male	Early detection and intervention clients experiencing sub-threshold psychotic features (e.g. auditory hallucinations)	n/a	Three central themes identified: 1) participants' perception of needs; 2) participants' journey through the service; and 3) participants' orientation towards their personal future.	Self selecting sample therefore possible positive bias
13. (C&C) Lester <i>et al.</i> , (2009). Development and implementation of early intervention services for young people with psychosis: case study. <i>The British Journal of Psychiatry</i> , 195, 35-40.	Multiple case study approach over 3 years	32 EIS clients, 18	Clients aged between	Client: Involved with	n/a	Key findings indicated EIS's were valued by clients' and carers'.	Case manager may have recruited a sample

of Psychiatry, 194, 446-450.	(2004-2006) involving staff, clients, carers and commissioners using interviews, written documents and demographic data to evaluate the development, implementation and impact of EIS's Interviews audio-taped & analysed using constant comparison method	Carers' 42 chief executives 70 team managers and staff *sample taken from 14 EIS's.	15-32, mean age-23. Carers aged between 35-72. Gender not reported.	EIS Carer: Involved with EIS through caring for a family member with FEP Professional: Involved in development or delivery of EIS		Experiences contrasted to previous negative experiences of care. Implementation of EIS's threatened unless consistent funding is made available.	with more positive views Participants' views consistently positive-approach findings with caution
14. (C&C) Callaly (2010). A qualitative evaluation of a regional early psychosis service 3 years after its commencement. Australian Health Review, 34, 382-385.	Service evaluation using observation, focus groups, interviews and questionnaires to establish fidelity to the EIS model and explore the attitudes of clients, carers and professionals towards the EIS	'11 patients and their families Number of professionals not reported	Age/gender not reported	Client: No information provided Carer: No information provided Professional: Involvement through referring, using or providing the EIS	Questionnaire (no further details provided)	Key themes were that the service was found to not adhere to its original design and EIS professionals experienced isolation from CMHTs. Findings also indicated 'comment on care was invariably positive' from clients' and families.	No detail provided on questionnaires and/or interviews. Inadequate reporting on process of data analysis, whether data saturation had been achieved and absence of major themes from data
15. (CA) Cabral and Chaves (2010). Multi-family group intervention in a programme for patients with FEP: a Brazilian experience. International Journal of Social Psychiatry, 56, 527-532.	Survey using questionnaires to investigate caregivers' knowledge about	40 caregivers	Mean age - 44. 38 female,	Carers involved with EIS through caring for a family	n/a	Key findings indicated 99% of participants believed the intervention helped them cope more	Lack of contrast group Inclusion of mainly

	psychosis / treatment and satisfaction with the intervention delivered		2 male	member with FEP		effectively, but 1/3 felt it had not improved their understanding of the illness/treatment	unemployed female carers Survey method produces data which lacks depth
16. (CL) Morton <i>et al.</i> , (2010). Promoting recovery: service user and staff perceptions of resilience provided by a new early intervention in psychosis service. Early Intervention in Psychiatry, 4, 89-92.	Survey evaluating whether clients and staff perceive the EIS to promote resilience and recovery	28 EIS clients, 7 EIS staff	Age not reported 6 female staff, 1 male staff member. Clients not reported	EIS clients who 'met the service criteria for FEP'	<i>Organizational Climate Component of the Developing Recovery Enhancing Environments Measure (DREEM)</i> (Ridgeway, 2005)	The findings indicated both clients and staff perceived the EIS as positively supporting resilience	Reliability and validity of organisational climate questionnaire not demonstrated Small sample size Bias in sample selection. Survey method produces data which lacks depth
17. (CA) McCann <i>et al.</i> , (2011). Primary caregivers' satisfaction with clinicians' response to them as informal carers of young people with first-episode psychosis: a qualitative study. Journal of Clinical Nursing, 21, 224-231.	Qualitative study design utilising semi-structured interviews with carers to explore their experiences of FEP clinicians. Interviews audio-taped and analysed using IPA	20 primary caregivers of individuals with FEP	Age not reported. 'Most' reported to be female	Primary caregivers involved with FEP service through caring for a family member with FEP	n/a	Two key findings were identified; 1) staff experienced as approachable and supportive, and 2) feeling their contribution was undervalued highlighting carers contrasting experiences	Recruitment through case managers may have lead to a sample with less critical views. Most of the sample were female. Males may have different conceptualisations Queries over Australian FEP service

							comparability to UK EIS
18. (CA) Riley <i>et al.</i> , (2011). Carers' education groups for relatives with a first episode of psychosis: an evaluation of an eight-week education group. Early Intervention in Psychiatry, 5, 57-63.	Qualitative study design utilising focus groups with carers to evaluate a carers' group within the EIS. Focus groups were audio-taped and analysed using thematic analysis	12 carers of individuals with FEP	Age/gender not reported	Carers involved with EIS through caring for a family member with FEP	n/a	Five key themes were identified: the emotional impact of being a carer (e.g. shock), the wider impact of mental illness (e.g. stigma, isolation), the impact of the caring role, barriers to and impact of EIS carer groups (e.g. increased confidence, greater understanding of psychosis)	Large numbers within the focus groups may have prevented some participants' participation
19. (CA) McCann <i>et al.</i> , (2011).First-time primary caregivers' experience accessing first-episode psychosis services. Early Intervention in Psychiatry, 5, 156-162.	Qualitative study using interviews to explore carers' experiences of accessing an EIS. Interviews audio-taped and analysed using IPA	20 carers	Mean age – 49 17 female, 3 male	Carers involved with EIS through caring for a family member with FEP	n/a	Key themes identified: GPs experienced as either resourceful or unresourceful, numerous barriers to accessing EIS's and caregivers development of strategies (e.g. assertiveness) to access services	Case managers may have recruited a sample with less critical views Most participants were female. Possible that males may have different experiences. Queries over Australian FEP service comparability to UK EIS

1.5.3.2 Clients' Views, Experiences and Satisfaction with Early Intervention for Psychosis Services

Seven studies reported clients' views, experiences and satisfaction with EISs. The first study explored 12 service users' experiences of a UK first episode for psychosis service (FIRST), using a focus group evaluation (O'Toole *et al.*, 2004). Three focus groups, each comprising of four FIRST clients who had a diagnosis of schizophrenia or schizoaffective disorder, were run by an independent facilitator, and audio-taped and analysed using Interpretative Phenomenological Analysis (IPA). The findings indicated that clients felt fortunate to be involved with FIRST services due to their previous negative experiences of mental health care, and experienced the 'human touch' by staff (incorporating collaborative working, being treated as a person, personalised care, being listened to, understood and cared for), as key to their engagement and recovery. In addition, clients also valued the flexible approach, staff availability, being treated in context and the provision of structure. Many said that they had experienced a reduction in psychotic symptoms and increases in confidence and independence as a result of the service. Whilst these study findings are significant in advancing knowledge as they are the first systematic qualitative evaluation of clients' experiences of an EIS, there are limitations within the research which suggest a need to approach the findings with some caution. Such limitations include the relatively small and self selecting sample and the more general challenges inherent within focus groups, such as the risk that the views captured may not necessarily represent the views of all group members. Furthermore, the views expressed by the participants were consistently positive, once again suggesting that these findings may need to be viewed with caution.

As mental health services continued to implement EISs across the UK, further research was carried out to investigate the effectiveness of EISs on outcomes. One such study was an investigation of an EIS on clinical and social outcomes, and on service user satisfaction (Garety *et al.*, 2006). This involved 144 people aged 16-40 years with first episode non-organic or affective psychosis being randomised to either standard treatment (CMHT care) (n=73) or an EIS (n=71) for 18 months. With regard to satisfaction, explored using the *Verona Service Satisfaction Scale* (Ruggeri and Dall'Agnola, 1993), there was a significant effect favouring the EIS group, with differences attributable to the manner, competence and listening abilities of EISs' staff. Whilst this study is one of the

first UK RCTs exploring the effects of an EIS, and therefore adds to understanding and provides valuable support for EISs' policy, there are a number of study limitations, such as the underpowered sample size and lack of researcher blinding. Furthermore, the concept of satisfaction is arguably complex (Williams, 1994), with Likert scales providing relatively little detail in comparison to more in-depth qualitative methods of inquiry.

The third study involved a mixed methods design, involving a series of measures, such as the *Positive and Negative Symptom Syndrome Scale (PANNS)* (Stanley *et al.*, 1986), the *Health of the Nation Outcome Scale (HoNoS)* (Wing *et al.*, 1998), questionnaires and interviews to investigate the effectiveness of a New Zealand EIS (Theuma *et al.*, 2007). The sample comprised of 100 EIS clients who were experiencing first episode symptoms of schizophrenia as described by the DSM- IV-TR (APA, 2000), and data were collected at five time points over two years. The findings indicated that there was no significant relationship between DUP and symptom severity or *HoNoS* scores, but improved outcomes were associated with high engagement and length of contact with the EIS. It was also reported that clients were particularly satisfied with staff availability, friendliness, and the psycho-educational and collaborative approach taken. A further finding was that some clients perceived that staff understood and were caring towards them, although others reported a sense of feeling pressured, for example, into taking prescribed medication. Whilst such findings had clear implications for clinical practice, there were limitations to this study. These included the absence of a control group, outcome measures being rated by EIS staff, thus introducing the possibility of bias, relatively small numbers of participants involved in the questionnaires (n=13) and interviews (n=4), and the absence of rigorous qualitative data analysis.

The fourth study within this area involved a person centred ethnographic study of 15 clients diagnosed with a serious mental illness within the 'schizophrenic spectrum' from a Danish EIS (Larsen, 2007). The objective of the study was to 'discuss the value of a social science perspective of interpretative understanding and existential phenomenology to study socio-cultural processes in a complex intervention' (Larsen, 2007, p. 333) and used observation and repeated interviews over a 2 year period. The results indicated that following FEP, many clients experienced an existential crisis (e.g. a destabilisation of their sense of self), and that the EISs enabled clients to develop a greater sense of self,

understand their current difficulties and develop realistic expectations for their future. The findings also demonstrated the importance of the type and quality of relationships with staff (e.g. authoritarian vs. equalitarian). Whilst this ethnographic research offered a comprehensive longitudinal evaluation of an EIS and extremely rich insights, because of this 'thick' description, and also the substantial differences between Danish and UK EISs (i.e. Danish EISs are provided for 2 years) it is difficult to generalise such results across clients and situations. Furthermore, more general limitations concerning the study design are that it may be too subjective and not sufficiently rigorous (Brown, 2007).

First person perspectives on EISs were also explored in an unpublished UK doctoral dissertation (Collishaw, 2007). This study aimed to explore the experiences of EIS of 12 clients with first episode symptoms of schizophrenia under the DSM- IV-TR (APA, 2000). Data collection involved individual interviews (n=12) and focus groups (using n=6 of the initial sample), which were audio-taped and analysed using Grounded Theory (GT). The results revealed three interrelated core categories, which appeared almost entirely positive. These core categories were: i) the features of engagement, which comprised factors which challenged (e.g. worries of an unknown service) or facilitated engagement (e.g. encouragement from family); ii) the day to day experience of the EIS, which encompassed factors which clients experienced as facilitating a sense of security (e.g. staff listening, understanding and availability) and promoting recovery (e.g. greater understanding of illness and increased activities); and iii) the features of moving on from the service, which included the factors (e.g. increased confidence, future plans) and feelings (e.g. fears and sadness) associated with moving on. Whilst this study does have value, as there are clear implications for clinical practice and service development, it is also apparent that there are limitations to the study. These include the sampling method utilised (via case managers) which may have recruited participants with more positive views, and additionally the questionable quality of the research (as this study has not been peer reviewed). However, doctoral dissertations are typically subjected to close scrutiny and are generally of good quality (Moyer, 2010) and as such merited inclusion. Furthermore, the views expressed by the participants were consistently positive, and thus it is recommended that these findings be viewed with a degree of caution.

In 2009, a qualitative study by Hardy *et al* explored clients at risk of developing psychosis and their experiences of the journey through an American early detection and

intervention for psychosis service. This service offered psycho-social interventions and pharmacological treatment. The sample comprised of 10 participants experiencing sub-threshold psychotic features and involved semi-structured interviews which were audio-taped and analysed using GT. The findings identified three central themes: i) 'perception of needs', which encompassed how participants recognized the need to access services and what was received (e.g. psychological needs being met, normalising, increased management strategies), ii) participants' subjective journey through the service (e.g. drawing on personal resources, such as family support or inner strength); and iii) participants' orientation towards the future (e.g. future goals and fears about issues such as employment or housing). Whilst this study does provide valuable insights into clients' subjective experiences, the findings must be interpreted with some caution due to the possible positive bias attributable to the self selecting sample. This study also highlights the differences across EISs with regard to variations in service models and delivery across different contexts. These are particular problems in making comparisons between international services.

The final study investigated clients with FEP (n=28) and staff members (n=7) with regard to their perceptions of resilience following their involvement in a UK EIS (Morton *et al.*, 2010). The measure used was *the Developing Recovery Enhancing Environments Measure (DREEM) Organizational Climate Component* (Ridgeway, 2005). The results indicated that both clients and staff perceived the EISs as positively supporting resilience through providing choices, valuing people, and having staff who cared, instilled hope and provided opportunities for meaningful participation. However, whilst such results are encouraging in suggesting that EIS's promote resilience after FEP, it is notable that the psychometric properties of the *Organizational Climate Questionnaire* are yet to be established, and the small sample size limits the generalisability of the findings to other EISs.

1.5.3.3 Carers' Views, Experiences and Satisfaction with Early Intervention for Psychosis Services

Six studies reported carers' views, experiences and satisfaction with EISs. The first study involved a service evaluation, using a series of measures including: *Knowledge on Schizophrenia Illness* (Barrowclough and Tarrier, 1995), the *Carers' Assessment of Managing Index* (Nolan *et al.*, 1995), the *Experience of Caregiving Inventory* (Szmukler *et al.*, 1996), and a semi-structured questionnaire to evaluate the experiences of carers in an EIS family intervention (FI) (Sin *et al.*, 2007). Specifically, this FI provided psycho-education and support to carers and families. The sample was taken from an EIS in the UK, but the sample size was not reported. The findings reported within the study were limited. The results from the measures were not included, and only a brief summary of qualitative feedback from the questionnaire was provided. However, the information that was available highlighted carers' general satisfaction with the EISs' FI group, as a result of the group providing social support, developing knowledge/understanding and instilling hope. Whilst this paper does provide support for service development regarding services for carers of individuals with FEP, this research has a number of limitations. These include the sparse information provided regarding the methodology (e.g. sampling procedure, participants' demographic information, psychometric properties of the measures, and ethical considerations) and the process of data analysis. There was no clear statement of the findings, and limited data supporting the interpretations. In addition, the study only reports participants' experiences of one particular component of an EIS (e.g. FI).

However, a qualitative study exploring carers' experiences of support from an EIS appeared to counter the limitations of the previous study (Penny *et al.*, 2009). The study involved 11 participants from 6 British Pakistani families in a UK EIS who were involved in caring for family members with FEP, and used in-depth interviews which were audio-taped and analysed using Interpretative Phenomenological Analysis (IPA). The findings identified three super-ordinate themes: i) 'a story of loss', encompassing a sudden realisation that help was needed, loss of hope, loss and persistent worry; ii) 'a social problem' involving the psychosis having a social or spiritual cause, and; iii) 'divergent points on the path to change' encompassing the importance of social and relational activities and faith to help deal with the difficulties. The findings also indicated

that the participants experienced the EIS as being solely about medicine due to communication difficulties. However, whilst the findings have important implications for policy and practice, particularly highlighting the importance of using interpreters to deliver the psycho-social and psychological interventions, such findings may be specific to British Pakistani families. In addition, the use of group interviews with families may have resulted in views which did not necessarily represent the views of all members, either because some group members may have dominated and/or because there was a pressure to provide socially desirable responses.

The third study investigated 40 caregivers of family members with FEP in a Brazilian EIS (Cabral and Chaves, 2010). The focus was on satisfaction with and knowledge acquired from a multi-family group intervention, involving psycho-education and support. Data was collected using a Likert scale satisfaction questionnaire and one open-ended question. The findings were reported using descriptive summary statistics and indicated that 99% of participants believed the intervention helped them cope more effectively and 95% approved of the format of the intervention. However, one third felt that the intervention had not improved their understanding of the illness or treatment. These findings were important in indicating the value of help and support provided by the non-specific aspects of a FI over the psycho-educational components. However, there were a number of study limitations including the small sample size, lack of a contrast group and inclusion of mainly unemployed females. In addition, similarly to Sin *et al* (2007) the study only reports participants' experiences of the FI component of an EIS.

Carers' satisfaction was also explored by McCann *et al* (2011). This Australian study investigated carers' experience of EIS professionals. The sample comprised of 20 'mostly female' primary caregivers of individuals involved in FEP services, and involved semi-structured interviews, which were audio-taped and analysed using IPA. The findings identified two competing themes. These included: i) professionals being approachable and supportive (e.g. responsive to carers' needs, respectful, willing to listen, and accessible), and; ii) feeling undervalued as a carer (e.g. excluded because of confidentiality issues and feeling that their contributions were not being taken seriously). Whilst these study findings have value with regard to both practice and policy, the findings should be interpreted with some caution as the sample consisted of 'mostly women', who may have different conceptualisations of professionals than males, and the

sampling method (via case managers) may have recruited participants with more positive views. In addition, due to the limited information provided within the paper, it is unclear whether Australian FEP services are comparable to UK EISs.

Similarly to the studies by Sin *et al* (2007) and Cabral and Chaves (2010), the fifth study aimed to evaluate a carers' education group, delivered by a UK EIS for relatives of individuals experiencing FEP (Riley *et al.*, 2011). These groups provided psycho-education and general support. One focus group, comprising of 12 carers, was run by an independent facilitator, and audio-taped and analysed using the QSR NVivo 8 software package for thematic analysis. The results revealed five key themes: i) 'the emotional impact of being a carer' (e.g. loss, shock, acceptance, lack of support); ii) 'the wider impact of mental illness within a family' (e.g. isolation, stigma for the client and carer); iii) the impact on 'roles and relationships' (e.g. improving relationships with their relative); iv) the group design e.g. (barriers to participating, such as work or travel distance, course content), and; v) the wider impact of the group (e.g. the need for carer education, and the importance of sharing experiences). The findings also indicated the key benefits of the group to be: improved confidence, feeling less isolated, greater knowledge and understanding of mental health difficulties, and the skills to manage relapse. As the literature within this area is limited, this study offers valuable information for clinical practice regarding the benefits of such a group. Nevertheless, there are limitations, as the large numbers in the focus group (n=12) may have prevented some participants from contributing. A design using two smaller focus groups (e.g. n=6) may have been advantageous.

The final study investigated carers (n=20) of individuals with FEP and their experiences of accessing Australian first-episode psychosis services (McCann *et al.*, 2011). Data collection involved in-depth interviews which were audio-taped and analysed using IPA. The results identified three competing themes. These were: i) their experience of general practitioners as being helpful or unhelpful in accessing FEP services; ii) service focused (e.g. lack of funding) or carer focused (e.g. lack of knowledge) barriers to accessing FEP services and; iii) the impact of carers' knowledge, experience and assertiveness in enhancing access to FEP services. Whilst this study highlights the difficulties carers experience in accessing FEP services, and the need to improve awareness, availability and access to FEP services, there are several limitations to the study. These include the

fact that the sample consisted mainly of women, who may have had different experiences of accessing services than males, and the sampling method, (via case managers) which may have biased the recruitment of participants towards those with less critical views. Furthermore, as noted with respect to previous studies, the generalisability of the findings may be limited due to the variation of FEP services across contexts.

1.5.3.4 Clients' and Carers' Views, Experiences and Satisfaction with Early Intervention for Psychosis Services

Six studies reported clients' and carers' views, experiences and satisfaction with EISs. The first study involved a service evaluation of an EIS from the perspectives of consumers and providers (Fisher and Savin-Baden, 2001). The study involved individual interviews with clients with a diagnosis of schizophrenia or related disorder (n=5), one carer, and professionals (occupational therapists) (n=7) engaged in TIME, an occupational therapy initiative delivering psychosocial therapies (e.g. early intervention, FI and CBT) for young people experiencing FEP. The data were analysed using IPA and demonstrated that clients and the carer experienced the service as supportive, collaborative, and individualised, which in turn, increased their confidence in managing their difficulties. Other themes included the importance of being listened to, meeting others who had had similar experiences, having meaningful occupational roles, and the provision of information which enabled informed choices and consistency. Difficulties with past mental health services were also highlighted. However, whilst the findings suggest the value of such services and highlighted the need for the development of policies to support the standards identified in the Mental Health NSF (DoH, 1999), there are limitations to the study. Primarily, it is unclear how the TIME initiative maps onto the EIS key components as specified in the MHPIG (DoH, 2001). Thus doubts arise about whether the findings may be comparable to those relating to traditional EISs. In addition, the research was limited to a single site, involved only a small number of participants (e.g. 1 carer), and may have been more realistically evaluated using a longitudinal study design.

The second study was a mixed methods study using semi-structured interviews and rating scales to explore the satisfaction of family members (n=19) and clients with FEP (n=4) with a UK family interventions in psychosis service providing FI and CBT

(Stanbridge *et al.*, 2003). The quantitative analysis (e.g. summary statistics) and thematic analysis of the data indicated that, despite initial high levels of apprehension about the service due to previous negative service experiences, high levels of engagement and satisfaction (74% 'very satisfied') were reported. In addition, participants reported that the service had enabled them to cope more effectively with difficulties (57% 'much better') and with their family members' symptoms (39% 'much better'). They also reported that they particularly valued developing greater understanding of mental illness and the collaborative working of the team. Positive qualities of the therapists, such as their understanding, ability to listen, and openness, were also found to be important. However, similar to the research by Fisher and Savin-Baden (2001), comparisons with other EISs (as defined by the MHPIG (2001)) are problematic as it was unclear whether the service offered pharmacological treatment. There are also limitations related to the relatively low number of clients involved in the study, limited statistical analysis on the data and the use of group interviews with families may have resulted in views which did not necessarily represent the views of all members, either because some group members may have dominated and/or there was a pressure to provide socially desirable responses.

Similarly to the study reported by Fisher and Savin-Baden (2001), the EDEN study (Birchwood *et al.*, 2006) also involved a service evaluation and aimed to evaluate the development and impact of EISs across the West Midlands (UK). This multi-case study used case note data and interviews with clients with FEP (n=32), carers of individuals with FEP (n=18), health executives (n=42) and EIS professionals (n=162) from 14 EISs. The interviews were audio-taped and analysed using constant comparative analysis. The findings regarding the health professionals are beyond the limits of this study. However, key findings regarding clients' and carers' experiences will be discussed respectively. The key themes arising from clients indicated that the majority felt anxious at the prospect of being involved with an EIS, were unsure of what to expect and were initially suspicious, based on their negative previous experiences of mental health services. Many also reported issues of stigma associated with using an EIS, limited self confidence and fears about whether recovery was possible. However, the majority reported that their involvement had been positive, highlighting, in particular, support with relapse prevention, meaningful occupation, positive relationships with particular members of staff who were there throughout their journey, re-establishment of confidence and

gaining new approaches to life. The majority of carers reported high levels of satisfaction with the EIS, particularly with respect to staff availability, flexibility of appointments, reassurance, support and improved confidence. However, some carers identified problems with lower than expected levels of contact. Whilst these study findings were valuable in regards to EISs' policy and practice, the results should be approached with some caution as the sample came from only one geographical area in the UK, consisted mainly of female carers (n=14), and the sampling method, (via case managers) utilised may have recruited participants with less critical views.

A further service evaluation of clients' and carers' perspectives of a UK EIS, in relation to 'best practice guidelines', was conducted by Naik and Bowden (2008). This study involved a questionnaire, based on good practice guidance (DoH, 2001), which was worded as a series of positive statements which could be agreed or disagreed with using a Likert scale. This was sent to clients (n=21) and carers (n=32) engaged in an EIS. The results indicated that both clients and carers perceived the EIS to meet good practice guidance. The guidelines which were perceived to be most closely adhered to were: usefulness of initial contact with EIS and support (*carers*), improved knowledge, understanding and daily structure (*clients*) and satisfaction with time, location, duration and frequency of appointments (*clients and carers*). However, the findings also indicated areas for service improvement, such as increasing awareness of and access to EISs, ensuring clients' involvement in their treatment, and instilling hope for carers. Whilst such findings demonstrate important implications for EISs' policy and clinical practice, there were several limitations of the study. These included the scale being open to bias of a set response type and an absence of any statistical tests of reliability. In addition, challenges inherent in the survey design include a self selection bias and inflexibility of the questions, potentially leading to ambiguous data sets.

Like the EDEN study (Birchwood *et al.*, 2006), Lester *et al* (2009) also adopted a multiple case study approach over three years. This research involved EISs' clients (n=32), carers (n=18), and health professionals (n=122), and used interviews, written documentation (e.g. annual reports) and demographic data to evaluate EISs in the UK. All interviews were audio-recorded and analysed using a constant comparison method. The findings regarding the health professionals are beyond the limits of this study. However, key findings regarding clients' and carers' experiences will be discussed

respectively. The findings indicated that the majority of clients were anxious at the referral to the EIS and concerned about the stigma associated with having a mental health difficulty/involvement with services. Many described negative past experiences of mental health care in contrast to the positive experience provided by the EIS highlighting the importance of continuity of care, expertise, and a feeling that staff cared. Several clients noted that the EIS had reduced their fears about the future and increased their self confidence. Similarly, carers were also satisfied with the care provided by the EIS, and compared these services favourably with previous mental health services. The flexibility, availability, support and hope offered by staff were also valued. Whilst this study offered multiple views of those experiencing the EIS, the study limitations include the sampling method (via case managers) which may have recruited participants with less critical views and, notably, an absence of any negative comments from participants.

A further service evaluation of an Australian EIS investigated the fidelity of the service to the EIS model and attitudes of EISs clients, carers and professionals towards the service (Callaly *et al.*, 2010). This study involved case note data, focus groups, interviews and questionnaires with “11 patients and their families”. The number of professionals was not specified. Whilst the results indicated poor fidelity to the original EIS model, it was highlighted that both clients and carers experienced the service as ‘positive’. However, there appeared to be significant methodological limitations with this study. These included limited information regarding the sample (e.g. selection procedure or participant demographic data), a lack of clarity regarding whether the interviews or focus groups had been audio- recorded, limited discussion of the process of analysis and the issue of whether data saturation had been achieved, and the absence of any report on major themes (and supporting data) arising from the analysis.

1.5.4 DISCUSSION

1.5.4.1 Synthesis of Research Findings

For both clients and carers involved with EISs, the majority of the research literature demonstrated significantly higher satisfaction in comparison to previous mental health services (Garety *et al.*, 2006; Lester *et al.*, 2009), the value of a psycho-educational approach (Fisher and Savin-Baden, 2001; Riley *et al.*, 2011; Theuma *et al.*, 2007) and, particularly, the importance of positive therapeutic relationships with staff (Birchwood *et*

al., 2006; Collishaw, 2007; Fisher and Savin-Baden, 2001; Larsen, 2007). Key elements of positive working relationships appeared to include collaboration, feeling listened to and cared for (Lester *et al.*, 2009; Morton *et al.*, 2010; O'Toole *et al.*, 2007), and involved professional strategies such as understanding, friendliness, 'being there' and flexibility (Birchwood *et al.*, 2006; Naik and Bowden, 2008; O'Toole *et al.*, 2007) as well personal qualities of the professionals (Stanbridge *et al.*, 2003). In addition, the impact of EISs on clients and carers is also evident in the reports of increased self confidence and development of knowledge and coping strategies (Birchwood *et al.*, 2006; Collishaw, 2007; Larsen, 2007; Lester *et al.*, 2009); O'Toole *et al.*, 2004; Riley *et al.*, 2011). Despite the fact that most of the literature indicates predominantly positive views, some literature does also indicate clients' negative experiences of EISs, (e.g. feeling pressured) (Theuma *et al.*, 2007), and carers' more tenuous relationship with the service (McCann *et al.*, 2011; Sin *et al.*, 2005).

1.5.4.2 Methodological Considerations

Overall, the number of qualitative studies within this area is relatively limited. It appears that little theory is being generated empirically and there are numerous limitations within the existing evidence base. These include methodological limitations, such as inadequate samples (e.g. gender biased carer samples), sampling methods which may have recruited participants with less critical views, questionable methods of data collection within a topic which may be complex and/or sensitive (e.g. Likert scales, questionnaires with poor psychometric properties, or group interviews) and insufficiently rigorous data analysis. Furthermore, the majority of studies involving carers have focused on an individual component of EIS, specifically FI, and thus their experiences of EISs overall continue to be under-researched. In addition, many studies did not report participants negative views of EIS and/or include an adequate discussion for the finding that there were no negative views. Indeed, few studies met the basic qualitative research/quality criteria and methodological limitations were rarely reported by the authors. However, it is accepted that the paucity of studies within this area may be partially attributable to EISs being relatively recent.

1.5.4.3 Implications for Practice

The evidence base reviewed regarding the experiences of clients and carers suggest that EISs are experienced as a positive way of delivering care for people with FEP and their families (Birchwood *et al.*, 2006; Garety *et al.*, 2006; O'Toole *et al.*, 2004; Sin *et al.*, 2007). This review of the literature also highlights a number of implications for clinical practice, such as the importance of early engagement, strategies to promote the development of positive therapeutic relationships (Larsen, 2007; O'Toole *et al.*, 2004; Theuma *et al.*, 2007), and providing interventions, in context, in a flexible, collaborative and empowering manner (Collishaw, 2007; O'Toole *et al.*, 2004). It is also apparent that caregivers may experience particular difficulties in their role as carers (Penny *et al.*, 2009; Riley *et al.*, 2011). The evidence suggests that carers may benefit from supportive and psycho-educational approaches that demonstrate value for their role (McCann *et al.*, 2011), instil hope (Sin *et al.*, 2007) and improve confidence, knowledge and skills in dealing with their family members' relapses (Riley *et al.*, 2011).

Furthermore, it is apparent that there continues to be a lack of knowledge about psychosis, both by mental health professionals and by lay people (Singh, 2010). Thus, many individuals may delay accessing support due to limited knowledge of the condition and of what help is available (McCann *et al.*, 2011), in addition to the stigma-driven reluctance to contact services (Birchwood *et al.*, 2006). There are also a number of service focused barriers such as limited service provision due to inadequate resources (McCann *et al.*, 2011). This highlights the need to improve awareness, the availability of and access to EISs, and the need for campaigns to promote public understanding of psychosis and to reduce stigma.

1.5.4.4 Implications for Research

This review indicates that whilst some initial exploratory research has been conducted within this area, there is a clear need for further qualitative, potentially user-led research exploring both clients' and carers' experiences of EISs. Indeed, user-led research may enable a more valid picture of services (Staniszewska and Ahmed, 1999). Research should address and counter the limitations identified in the existing evidence base (see section 1.5.4.2), such as obtaining an adequate sample, using appropriate data collection methods to explore the topic in-depth, providing a comprehensive description of the

analysis process and exploring individuals' positive and negative experiences (CASP, 2001). The essential components of the EIS should also be provided to enable comparison with other studies of different EISs. Such qualitative research is particularly important given the government emphasis on improving the quality of service from the perspective of the users (Birchwood *et al.*, 2006).

1.5.4.5 Conclusions

Overall, this systematic literature review clearly indicates that whilst there is some qualitative research exploring clients' and carers' experiences of EISs, the evidence base is limited and much of it is of questionable quality. Thus further qualitative research to investigate and report clients' and carers' experiences of EISs in a rigorous manner, may generate useful understanding and provide an important contribution to the existing evidence base. Indeed, a greater understanding of consumers' experiences is pivotal in terms of developing this specialist service in helpful ways.

1.6 THE CURRENT STUDY

1.6.1 Rationale for the Current Study

The impact of psychosis on the individual and on family members can be substantial (Fisher *et al.*, 2004; Stein and Wemmerus, 2001). Recent evidence suggests that individuals with a first episode of psychotic illness are at a high risk of suicide (Fedyszyn *et al.*, 2010), whilst caregivers often report feelings of hopelessness (Shore, 2006), stress (McGorry, 2000) and depression (Kuijpers and Raune, 2000).

Whilst quantitative research evidence confirming the superiority of EISs over standard CMHT care in managing FEP has increased (Craig *et al.*, 2004; Garety *et al.*, 2006; Peterson *et al.*, 2005), qualitative research exploring clients' and/or carers' experiences of EISs appears to be more limited (Lester *et al.*, 2009; Naik and Bowden, 2008). Indeed, the majority of research into clients' and carers' experiences was conducted prior to the introduction of EISs, explored satisfaction levels across a range of services for psychosis, or is of poor methodological design (McKenzie, 2006). Consequently, relatively little is known about clients' or carers' experiences of an EIS.

Thus, the aim of this study is to explore clients' and carers' views and experiences of an EIS in order to develop an in-depth understanding of their subjective experiences of the service. This may encompass areas such as expectation of the service, engagement, relationships and recovery. Such research is vital as it may benefit future patient care by providing further understanding of an under-researched area and elicit information relevant for service development and delivery in collaboration with clients and carers.

1.7 CHAPTER SUMMARY

This chapter has reported and analysed the existing literature relating to the impact of psychosis, the effectiveness of EISs and the clients' and carers' experiences and satisfaction with such services. Whilst there appears to be a relatively strong evidence base regarding the effectiveness of EISs, qualitative literature exploring individuals' subjective experiences of the service is limited. Thus little is known about how clients and carers experience the EIS. An in-depth understanding of clients' and carers' experiences of early intervention is paramount in providing information relevant for service development and delivery.

CHAPTER TWO: METHODOLOGY

2.1 CHAPTER OVERVIEW

In Chapter One, an overview of the literature regarding psychosis and Early Intervention for Psychosis Services (EISs) and a systematic review of the literature pertaining specifically to clients' and carers' experiences of EISs was provided. This review indicated a dearth of qualitative research into clients' and carers' experiences of EIS. Therefore this phenomena is to be investigated in the current study. The researcher employed a qualitative methodology, in this instance Grounded Theory (GT) (Glaser and Strauss, 1967; Strauss and Corbin, 1990), to explore in detail clients' and carers' experiences of an EIS.

The following chapter details the design, method and procedure used in this study. This includes a description of the participants, and the process of data collection and analysis. An overview of the principles of qualitative methodology and GT are also provided alongside a rationale for the chosen methodology. Issues of ensuring quality in qualitative research and ethical considerations are also discussed.

2.2 QUALITATIVE METHODOLOGY

2.2.1 Principles of Qualitative Methodology

Qualitative methodologies are increasingly being utilised in research to understand the complexity of human behaviour (Draper, 2004; Elliott *et al.*, 1999). This increase reflects a shift away from the more traditional quantitative method of inquiry. In regards to philosophical basis and research aims, quantitative and qualitative methods differ significantly. Quantitative research is rooted in positivism and aims to test hypotheses and establish cause and effect through the collection and analysis of numerical data. In contrast, qualitative research is broadly rooted in the interpretative tradition and aims to describe and explain social phenomena as they occur in their natural context by collecting and analysing narrative data (Draper, 2004). Qualitative research is concerned with the 'quality and texture of the experience... how people make sense of the world and how they experience events' (Willig, 2008, p. 8).

In quantitative research, hypotheses inform the direction of the study. This is known as the hypothetico-deductive method (Willig, 2008). However, qualitative research is guided by provisional research questions. Such questions identify the phenomenon under investigation and guide the way in which research is conducted without predicting the findings (Willig, 2008). Commonly open ended questions which elicit detailed descriptions of phenomena under investigation, are utilised to explore these research questions (Draper, 2004). Semi-structured interviews appear to be the most widely used data collection tool in qualitative research with other methods, such as observation, focus groups or diaries used to a lesser extent (Willig, 2008).

2.2.2 Rationale for Qualitative Methodology

A qualitative methodology was deemed appropriate for the current study for several reasons. Primarily, this was because, as outlined in Chapter One, there is a limited knowledge base within this field. Thus, a qualitative approach, which seeks to facilitate an exploration into phenomena on which relatively little is known, was considered more appropriate than a quantitative methodology which aims to test out preconceived hypotheses based on the existing literature (Stern, 1980). Furthermore, as the study was concerned with individuals' *experiences* it was considered that quantitative methods would not enable the researcher to capture the phenomena easily or explore it at sufficient depth. Therefore a qualitative GT methodology, which enables an exploration of the meaning and understanding of individuals' experiences (Henwood and Pigeon, 1995) was considered more appropriate. This particular research method was selected to explore and structure accounts of clients' and carers' experiences of an EIS. The intention was that, through inductive reasoning, a theory of clients' and carers' experiences of an EIS may emerge which would potentially increase understanding and improve service provision.

2.3 GROUNDED THEORY

2.3.1 Principles of Grounded Theory

Grounded Theory aims to generate explanatory theories of basic social processes studied in context (Glaser and Strauss, 1967) and refers to both 'the process of category

identification and integration (as *method*) and its product (as *theory*)’ (Willig, 2008, p. 35).

In contrast to other research methods, the GT approach merges the processes of data collection and analysis in order to ‘ground’ the analysis in the data (Willig, 2008). Whilst GT data collection may take many forms, such as semi-structured interviews, focus groups, observation or diaries (Willig, 2008), the process of GT allows the researcher to move between data collection and analysis and continue until *theoretical saturation* (i.e. the point when no further categories are identified from data collection and analysis) has been achieved. Further strategies such as theoretical sampling, the process of collecting further data in the light of categories that have emerged from prior data analysis, are also utilised (Sandelowski, 1995b). This provides the researcher with a means of ‘checking emergent theory against sampling incidents that may challenge or elaborate its developing claims’ (Willig, 2008, p.37).

2.3.2 Grounded Theory Analysis

Grounded theory analysis involves data being analysed according to a *coding paradigm* (i.e. a system of coding that seeks to identify causal relationships between categories) (Willig, 2008). The procedure described below is based upon procedures and techniques by Strauss and Corbin (1990). This was adopted as a framework for data analysis within this study.

2.3.2.1 Coding

Coding is the process of ‘extracting concepts from the raw data and developing them in terms of their properties and dimensions’ (Strauss and Corbin, 1990, p. 159). There are several stages within this process. These are discussed below (see Appendix 1 for an excerpt of a coded transcript).

2.3.2.2 Open Coding

Open coding is the process of naming and categorising phenomena in order to develop the basic units of analysis-*concepts* (Strauss and Corbin, 1990). The researcher endeavoured to use ‘in-vivo’ labels to maintain the semantics of the data (Willig, 2008).

2.3.2.3 Axial Coding

Axial coding is the process by which data are put back together in new ways after open coding (Strauss and Corbin, 1990). This was achieved by the researcher utilising a 'coding paradigm' which aimed to identify connections between categories and sub-categories in order to understand the phenomenon under investigation (Strauss and Corbin, 1990).

2.3.2.4 Selective Coding

Strauss and Corbin (1990) define selective coding as 'the process of selecting the core category, systemically relating it to other categories, validating those relationships, and filling in the categories that need further refinement and development' (p.116). It is through this process that the categories were integrated and developed into the theory.

2.3.2.5 Memo writing

Theoretical memoing involved the researcher maintaining a written record of theory development (e.g. definitions of categories) throughout the process of data collection and analysis. This process enabled the researcher to keep track of their ideas in the evolving theory (Willig, 2008) (see Appendix 5 for examples of a memoing).

2.3.2.6 Theoretical Saturation

Grounded theory methodology advocates the process of data collection and analysis should continue until theoretical saturation has been achieved (Willig, 2008). This involved the researcher continuing to sample and code data until no further categories or insights emerged.

2.4 ENSURING QUALITY IN QUALITATIVE RESEARCH

As qualitative methods have become increasingly common in social science research, the debate regarding the legitimacy of these methodologies has intensified (Elliott *et al.*, 1999; Reicher, 2000). As the evaluative criteria applied to quantitative research are disputably not applicable in these contexts, a number of guidelines, specific to qualitative methodologies, have been developed to increase the quality and legitimacy of qualitative

research (Elliott *et al.*, 1999). These guidelines recommend that the study should demonstrate the following throughout the research process:

1. Owning one's perspective

The researcher should specify their theoretical, methodological or personal orientations to enable the reader to interpret the analysis and consider alternative understandings. A summary statement from the researcher is provided in section 2.4.1.

2. Situating the sample

The researcher should provide information describing the participants and their contexts to assist the reader in evaluating the range of people and situations to which the research findings may be applicable. Information pertaining to research participants is addressed in section 2.8.5.

3. Grounding in examples

The researcher should provide examples from the data to a) demonstrate analytic procedures and b) illustrate their interpretation of meaning. This enables the reader to appraise the fit between the data and the researcher's understanding. An example of an analysed transcript can be found in Appendix 4, whilst Chapter Three provides direct quotations from participants to illustrate emergent categories in the data.

4. Providing credibility checks

The researcher should employ methods, such as using an additional analyst, to check the credibility of their findings. Both of the researcher's supervisors, one of whom had extensive experience of working with EIS's clients and carers, provided support in reviewing the data and analysis and offered some elaboration to the initial analysis with regards to reflections on the importance of considering factors which helped or hindered the processes throughout the three core categories.

5. Coherence

The researcher should report understanding in a manner which a) enables the reader to understand the phenomenon and b) preserves the nuances in the data. Chapter Three provides such a framework; beginning with a diagram (see Figure 3.1) which depicts the relationships between concepts, categories and core categories and further provides a comprehensive verbal narrative around the ‘core category’ using examples from the data.

6. Accomplishing general versus specific research tasks

The researcher should provide a clear explanation regarding whether a general or specific understanding of a phenomenon is sought; thus addressing the issues of generalisability. The aims of the study (section 1.6.1) and clarification of principles of qualitative research (section 2.2.1) provide a clear understanding of the task of the current study.

7. Resonating with readers

The researcher should present the findings in a manner that enables the reader to connect with the narrative and perceive it to represent an accurate depiction of the researched phenomena. This was achieved by strategies such as the use of ‘in-vivo’ concept and category labels, constant memoing (to verify interpretations), and the submission of draft chapters to the researcher’s supervisors for feedback on the narrative of the experience under investigation.

2.4.1 The Researcher’s Perspective

It is advocated that the GT researcher should specify their own perspective to demonstrate transparency and enable to reader to interpret the analysis (Elliot *et al.*, 1999; Mays and Pope, 2000). Typically this statement should incorporate the researcher’s ‘theoretical orientations and personal anticipations ... their values, interests and assumptions’ (Elliot *et al.*, 1999, p.221). This is provided below.

The researcher is a single 31 year old White British female from a middle-class background in South-West England. The researcher has had experience of working in a

number of adult mental health settings (e.g. assertive outreach, forensic services) and has completed a post-graduate Masters degree in Mental Health. As part of the post-graduate course the researcher undertook a qualitative research study exploring clients' experiences of an assertive outreach service.

Prior to the present study, the researcher was aware of the EIS, but had had no formal contact with or in-depth knowledge of the service. The researcher became interested in the EIS after a case presentation from an EIS (at a Local Health Board Specialist Interest Group), which led to a visit to local services and an initial exploration of the EIS literature. It was during this initial foray into the research that the researcher discovered the dearth of literature regarding clients' and carers' experiences of the EIS. It was felt that it would be of value to learn about these experiences and a qualitative (GT) methodology would offer the means by which this could be fully explored. The researcher had not had any experience of working within the EIS service or had contact with any of the staff members employed within that service. However, post data collection and in the 'write up' stage of the study the researcher began a placement with an EIS in South Wales; although had no contact with research participants as part of her role as a health care professional.

The researcher also acknowledges, due to their past academic background (sociology), a potential position which incorporates a view that the label of schizophrenia (and diagnosis) is one that has been constructed through ideological systems, none of which are truly empirical, as there is no distinctive evidence as to the cause(s) of schizophrenia. However, as part of Clinical Psychology Doctoral training the researcher received training on the bio-psycho-social model of psychological difficulties. This enabled the researcher to hold in mind multiple perspectives about schizophrenia and psychosis and hold a 'curious' position when working and conducting research in an EIS which worked with such diagnoses and treatment. Nevertheless, the researcher was also mindful of how these personal perspectives may have influenced the data analysis e.g. interpretation of experiences of disempowerment and oppression through involvement in mental health services.

2.5 STUDY DESIGN

The study employed a qualitative research design and involved a series of semi-structured interviews with eight clients and five carers who were currently involved with an EIS. The purpose of the semi-structured interview was to elicit the participants' subjective experience of an EIS; including their expectations about the service, engagement, relationships and recovery. The interviews were transcribed and the data analysed using a GT approach (Strauss and Corbin, 1990).

2.5.1 Influence of a Key Paper on Study Design

The study design was influenced by a key paper (Collishaw, 2007) (see section 1.5.3.2 for study details). This study utilised a semi-structured interviews, focus groups and a GT methodology to explore the views of clients who attended an EIS day programme. The current aimed to build on this research and utilised semi-structured interviews and a GT approach to explore the experiences of those who utilised an EIS which adhered to the EIS principles specified by the DOH (2001) (e.g. treatment and care in a community setting). The purpose was to develop a fuller grounded theory of clients and carers experiences of an EIS (which was delivered in line with the principles recommended by the DoH (2001)) which offered further in-depth insights into the factors which helped or hindered the processes of engagement, continued involvement, recovery and transition from early intervention services.

2.6. SERVICE CONTEXT OF CURRENT STUDY

The specialist EIS that is the subject of the study reported here is part of the National Health Service (NHS). It operates across a large geographical area in South Wales and was established approximately 5 years ago. The EIS provides a service for people aged between 14-35 years with a first presentation of psychotic symptoms or during the first three years of psychotic illness. Specifically, the service aims to provide a comprehensive needs assessment to inform phase-specific interventions (e.g. pharmacological, psychological or psychosocial therapies) relevant to that individual and their environment, to promote optimism about recovery and to instil hope for individuals and their families. In addition, person-centred, collaborative intervention packages are offered which involve the carers in the recovery process and offer interventions in an

environment considered by the client to be the least restrictive, intrusive and stigmatising. The service philosophy and practice is based around the recovery model (Repper and Perkins, 2003).

The EIS team includes MDT professionals, consisting of one psychiatrist, one clinical psychologist and eight community psychiatric nurses. Working hours are between 9am to 5pm Monday to Friday. The team accepts referrals from child and adolescent mental health services (CAMHS), CMHTs and primary care services (e.g. General Practitioners).

The service currently provides support for approximately 140 clients and their families. Care coordinators typically hold caseloads of 15, and clinical contact ranges from daily contact to once per month, dependent on the individual's level of need and stage of recovery. A key EIS practitioner will typically remain involved with the individual and their family for three years, unless the client no longer wishes to be engaged with the service.

2.7 ETHICAL ISSUES

2.7.1 Ethical Approval

Prior to the research commencing, the researcher obtained approval from the Local Health Board Research and Development Units and the Local Research Ethics Committee. Letters of approval are attached (see Appendices 6 and 7).

2.7.2 Informed Consent

A participant information sheet outlining the study aims and procedure was developed for clients (see Appendix 8) and carers (see Appendix 9). This informed potential participants of the voluntary nature of participation in research, the right to withdraw from the study at any stage without penalty and the measures in place to ensure confidentiality throughout the research process.

A participant's consent form was also developed for use within the research study (see Appendix 10). This document sought to obtain written consent from the participants regarding the interview being audio-taped and the possibility of anonymised data collected during the study being included in the final report. Informed consent was

obtained several days prior to the interview and confirmed by the researcher on the day (of the interview).

2.7.3 Confidentiality

Issues of confidentiality were addressed using the following procedures. The researcher did not have access to any information about potential participants until they indicated, by return of the consent form, that they were willing to participate. These individuals were then contacted, by the researcher, by telephone, and a mutually convenient date and time was arranged to conduct the interview.

The researcher ensured that issues of confidentiality were fully explained in the participant's information sheet (see Appendices 8 and 9). These were re-iterated verbally prior to the commencement of the interview. Specifically, it was highlighted that all information would remain confidential, with the exception of participants' disclosures of risks to themselves, or to others, in which event the researcher would need to share that information with the relevant services in order to provide the participant with the appropriate support.

The researcher also ensured that any information that may have identified the participant was stored in a locked cabinet. To further protect participants' anonymity participants were allocated a pseudonym which was utilised in the written report. All other identifiable information, such as EIS staff names, was removed during transcription, with an 'x' used to signify a name. After the data had been analysed, the transcripts were stored in a locked cabinet (on an NHS site) and will remain there for five years before being destroyed (Data Protection Act, 1998).

2.7.4 Debriefing

The researcher provided participants with an opportunity after the interview to reflect on the interview process (Roberts *et al.*, 2004). Additional information about the study was also provided if the participant required. Participants were also reminded of the research protocols in place (as outlined in the participants' information sheet) to provide additional support in the event of distress arising from, for example, the recounting of past difficult experiences. In addition, participants were also informed that the findings of the study may be published in a peer-reviewed journal.

2.7.5 Dissemination of Research Findings

A summary of the research findings will be provided to the participating EIS and participants. The findings will be disseminated at both Local Health Board and National EIS events. It is also intended that the study will be submitted as an article for publication in a peer-reviewed journal publication. The thesis will be held in Cardiff University library.

2.8 RESEARCH PARTICIPANTS

As sample sizes in GT research are determined by ‘theoretical saturation’, the total number of participants required could not be predetermined. However, as GT studies tend to report sample sizes ranging between 10-15 participants (Starks and Trinidad, 2007), a sample of eight clients and eight carers was sought. An equal number was sought to obtain an equal perspective from both groups. Client-carer dyads (e.g. two individuals who are linked, such as a mother and daughter) were also included.

Selective sampling was used to recruit 13 participants (eight clients and five carers) and an initial analysis was completed on the data. Participants were recruited until no major new issues or themes appeared to emerge during the coding process. All the interviews were transcribed and analysed.

In order to address the research question, which aims to explore clients’ and carers’ experiences of an EIS, and ensure the safety and well being of participants, a comprehensive set of inclusion and exclusion criteria were developed. The specific criteria are discussed in detail below.

2.8.1. Inclusion Criteria

Client

1. Client who is supported by the EIS at the time of recruitment and interview and has been involved with the service for a minimum of 6 months.

Carer

1. An individual who is supporting a person currently involved in the EIS. The carer does *not* have to be a relative or living with the person they care for (DoH, 2001b).
2. The individual is considered by the team to be the primary named caregiver e.g. the person routinely registered in the statutory and voluntary agency records, or nominated by the client as their carer.
3. The carer has maintained regular recent contact with the client for the past three months.

2.8.2 Exclusion Criteria

Client

1. EIS staff judge that the clients' difficulties may make it problematic for them to comprehend/retain the information, thus making it difficult for them to give informed consent.
2. The client is detained under the Mental Health Act (1983) and / or is in an inpatient facility.
3. EIS staff judge that the individual poses a risk to themselves or others.
4. The client is not fluent in English.
5. The client is under 18 years of age.
6. Client has recently undergone or is undergoing assessment for organic psychosis or has a primary alcohol or drug addiction.
7. EIS staff judge that involvement in the research may exacerbate clients' current difficulties.

Carer

1. The carer is not fluent in English.
2. EIS staff judge that involvement in research may prove stressful for carer or indirectly exacerbate client's current difficulties.
3. The carer is under 18 years of age (DoH, 2001b).
4. The carer is paid for caring and/or a volunteer worker (DoH, 2001b).

5. EIS staff determine that the client does not consent for their involvement with the EIS to be described from the perspective of their carer.

2.8.3 Recruitment of Participants

After obtaining ethical approval, the researcher met with the EIS staff to discuss the proposed research, plan the recruitment process and identify protocols to ensure participants' safety e.g. procedures to manage emotional distress arising from the interview.

During this meeting, the researcher explained the inclusion/exclusion criteria and the rationale behind the sampling method. EIS staff agreed to pass on research information packs (containing a participant information sheet, informed consent form and stamped addressed envelope) to potential participants and to provide additional information about the study if this was required. The researcher also made EIS staff aware of the importance of allowing potential participants time to make their own decision to participate in the research. Potential participants were invited to contact the researcher if they had any questions about the study and requested to return the signed consent form by post in the stamped addressed envelope to the researcher within seven days if they wished to take part. This was to avoid over-recruitment. The researcher did not have access to any information about potential participants until they had indicated they were willing to participate in the study.

Following contact from potential participants, the researcher arranged a mutually convenient time and place to meet to conduct the interview. All interviews were carried out individually. Where client-carer dyads (e.g. two individuals who are linked) agreed to participate, they were seen individually to maintain confidentiality. In addition, client-carer dyad participants interviewed in their home environment were interviewed when the other (e.g. client or carer) were not present in the house.

2.8.4 Response Rate

The researcher was not present during the EIS process for identifying individuals who met the inclusion criteria or informed of the outcome. However, in total 60 research information packs (30 clients and 30 carers) were provided to potential research

participants. All members of the EIS (ten staff members in total) cooperated fully in the distribution of research information packs.

In total eight clients and five carers agreed to meet with the researcher and participated in the study. The duration of time between the initial contact by the EIS staff member providing the research information pack and the interview with the researcher was approximately two weeks.

2.8.5 Description of Participants

In order to aid the reader in judging the range of persons and situations to which the findings may be relevant, it is important, to 'situate the research sample' (Elliott *et al.*, 1999, p.221). Thus, below is a summary of each participant based on the information provided at interview. However, the need for transparency for the reader was considered alongside issues of confidentiality. Consequently, as there was a potential risk of recognition of research participants through their ethnicity, this data was omitted.

All participants were provided with pseudonyms to ensure confidentiality. Client – carer dyads are denoted by names beginning with the same letter e.g. *Rhiannon* and *Rebecca*.

Clients

Rhiannon was the first client to be interviewed. She is a 21 year old single female who lives at home with her mother (*Rebecca*) and her step-father. Rhiannon became involved with the EIS two and a half years ago when she experienced a psychotic episode after a number of stressful events at University. She has been given a diagnosis of Brief Psychotic Disorder (APA, 2000). She currently meets with Jemima (EIS Worker) once per month. She had no previous history of mental health difficulties. Rhiannon is currently working for a volunteer scheme which befriends older adults. Rhiannon has many ambitions for the future and hopes to work abroad in the film industry.

Dylan was the second client to be interviewed. He is a 21 year old single male who lives at home with his parents and siblings. Dylan became involved with the EIS 11 months ago after experiencing psychotic symptoms whilst living away from home with his friends and trying illicit substances for the first time. He has been given a diagnosis of Brief Psychotic Disorder (APA, 2000). He currently meets Jemma (EIS Worker) once

per week. Dylan has a family history of mental health problems. However, this was his first personal contact with mental health services. Dylan works for a volunteer scheme to support people with mental health problems.

Caddell was the third client to be interviewed. He is 34 years old and married to *Carys*. He lives with his wife and daughters. Caddell became involved with the EIS 16 months ago after experiencing psychotic symptoms after a number of work related stress issues. He has been given a diagnosis of Bi-Polar Disorder (APA, 2000). He currently meets with Jared (EIS Worker) once per week. Caddell had no previous history with mental health services. Caddell owns and manages his own business.

Bryn was the fourth client to be interviewed. He is a 31 year old single male who lives alone. Bryn became involved with the EIS 14 months ago after experiencing a psychotic episode after a number of stressful life events. He has been given a diagnosis of Schizophrenia (APA, 2000). He currently meets Jared (EIS Worker) once per week. Bryn works part time as a civil servant.

Aled was the fifth client to be interviewed. He is a 32 year old single male who lives alone. He has one daughter who lives in a nearby town. Aled became involved with the EIS two years ago after experiencing a number of psychotic symptoms which significantly impacted upon his functioning and levels of distress. He has been given a diagnosis of Schizoaffective Disorder (APA, 2000). He currently meets James (EIS Worker) once every two weeks. He is keen to get back into work and help his daughter pay for her wedding.

Dilwen was the sixth client to be interviewed. She is a 31 year old female married to *David*. They have two young children and close relationships with their extended family who live nearby. Dilwen became involved with the EIS three years ago after experiencing a psychotic breakdown after a series of traumatic family events. She has been given a diagnosis of Psychotic Depression (APA, 2000). She currently meets Joanne (EIS Worker) twice a month. Dilwen is keen to return to work in the catering industry.

Harri was the seventh client to be interviewed. He is 22 year old single male who lives with his parents. Harri became involved with the EIS two years ago after experiencing a

number of psychotic symptoms after several difficult life events. He has been given a diagnosis of Schizophrenia (APA, 2000). He currently meets Jemima (EIS Worker) once per month. Harri currently works part time as a civil servant.

Gareth was the eighth client to be interviewed. He is a 27 year old male engaged to his partner Genny. They have two young children. Gareth became involved with the EIS two and a half years ago after experiencing a psychotic breakdown after a number of stressful events. He has been given a diagnosis of Schizophrenia (APA, 2000). He currently meets Jack once per month. Gareth is currently working full time.

Carers

David was the first carer to be interviewed. He is 33 years old and married to *Dilwen*. They have two young children and close relationships with their extended family who live nearby. He currently works in an industrial setting. David became involved with the EIS three years ago when Dilwen experienced a psychotic breakdown after a series of traumatic family events. David and Dilwen currently meet Joanne (EIS Worker) together once per month. This was their first contact with mental health services.

Carys was the second carer to be interviewed. She is 33 years old and married to *Caddell*. They have children and live in a rural setting. Carys first became involved with the EIS 16 months ago after Clive experienced a psychotic episode after a number of stressful events at work. Carys and Caddell currently meet with Jared (EIS staff member) together twice per month. This was their first involvement with mental health services. Carys currently works in healthcare.

Rebecca was the third carer to join the study. She is 54 years old and recently re-married. Rebecca is the mother to *Rhiannon* and Rosa. Rebecca became involved with the EIS two and a half years ago when Rhiannon experienced a psychotic episode and was admitted to a psychiatric hospital. Rebecca and Rhiannon currently meet with Jemima (EIS staff member) together once per month. Rebecca is currently unemployed. Her faith is important to her and she spends much of her time involved in activities related to her Church.

Bethan was the fourth carer to be interviewed. She is 60 years old and recently remarried. Bethan currently works full-time in hospitality. Bethan is the mother to Brian

(age 26). She became involved with the EIS when Brian experienced a drug induced psychotic episode 12 months ago. Bethan and Brian currently meet with Josie (EIS staff member) together eight times per month. Brian had been living at home with his mother and step-father but has recently moved into supported accommodation.

Ffion was the fifth carer to be interviewed. She is 42 years old and single. Ffion currently works full-time in an educational setting. Ffion is the mother to Fane (age 19). She became involved with the EIS two years ago when Fane experienced a psychotic episode after moving away from home to attend university. Ffion and Fane currently meet Jemima (EIS Worker) twice per month. Fane is currently living at home and attending college.

2.9 DATA COLLECTION

2.9.1 Semi-Structured Interview

Semi-structured interview schedules for clients (see Appendix 11) and carers (see Appendix 12) were developed through consultation with the researcher's (clinical and academic) supervisors and reading relevant literature. This method allowed participants to talk about their experiences and formed a broad guide for the researcher during the interview (Del Busso, 2004). The researcher used open ended questions, alongside expanding and exploratory prompts, to ensure flexibility throughout the course of the interview. The interview was developed around 'stem' issues. These included:

1. Participants' experiences of becoming involved with the EIS
2. Participants' experiences of the EIS (e.g. staff, other clients/carers)
3. Participants' expectations for future involvement with the EIS

The duration of the interviews was between 30 minutes to 1 hour. The interviews were conducted in the participants' home environment.

However, GT methodology proposes that the researcher is involved simultaneously in data collection and analysis (Willig, 2008). Therefore the interview questions altered in focus after the analysis of the initial interview transcripts to include, for example, issues such as:

1. The emotional impact of the breakdown
2. Participants' previous experiences of mental health services

2.10 DATA ANALYSIS

Data analysis was conducted soon after data collection in accordance with the iterative nature of GT (Strauss and Corbin, 1990). Each interview was transcribed verbatim and analysed within 48 hours according to the processes outlined in section 2.3.2. The transcripts were coded, initially line by line, and then each of the codes were grouped with similar codes looking at similarities and differences in themes. Emergent ideas informed future directions of inquiry during interviews. Memos were utilised to facilitate this process. As data analysis progressed, emergent categories were then grouped together with related key concepts in diagrammatic trees and core categories emerged from the analysis (see Figure 3.1).

2.11 CHAPTER SUMMARY

The researcher utilised a qualitative methodology, specifically a GT approach, to 'discover' and understand clients' and carers' experiences of an EIS. In total 13 individuals (eight clients and five carers) participated in the research study. A semi-structured interview was used to collect the data. All interviews were audio-taped and the data were transcribed in accordance with principles of GT analysis (Strauss and Corbin, 1990). The following chapter presents the results of the data analysis.

CHAPTER THREE: RESULTS

3.1 CHAPTER OVERVIEW

This chapter presents the results of the qualitative analysis of the data collected from 13 participants interviewed about their experiences of an Early Intervention for Psychosis Service (EIS). The data were analysed using a Grounded Theory (GT) approach (Strauss and Corbin, 1990) and organised into series of hierarchical relationships between **CORE CATEGORIES**, **categories**, sub-categories, and *concepts*.

A diagrammatical representation of the results is presented in Figure 3.1. This diagram demonstrates the relationship between the three **CORE CATEGORIES**: 'Engagement', 'Ongoing Involvement', and 'Towards Independence', eight categories and eighteen sub-categories. The concepts are shown in separate tree diagrams in Figures 3.2. to 3.4. For clarity, the findings are presented using the following format. Each **CORE CATEGORY** is presented in emboldened capitals; **category** is presented in emboldened lowercase; sub-category is presented in underlined text and *concepts* are presented in italic type face. Downward arrows denote the hierarchical relationship between **CORE CATEGORIES**, **categories**, sub-categories and *concepts*. Each **CORE CATEGORY**, (**category**, sub-category and related *concepts*) is also presented in a separate hierarchical tree diagram (Figures 3.2 to 3.4). These are presented in turn, and in this order, throughout this chapter alongside definitions and illustrative quotes from the data.

All identifiers have been removed from the quotations and pseudonyms have been allocated to all participants. As outlined in the methodology, client-carer dyads' have been allocated with pseudonyms starting with the same letter, e.g. 'Carys' and 'Caddell'. In addition all the EIS staff members have been allocated with pseudonyms beginning with the letter 'J' e.g. 'James'.

A small number of *concepts* refer only to clients. This is clearly stated in the associated narrative, and additionally noted in the *concept* heading with 'CL'.

Figure 3.1 Core concepts, Categories and Sub-categories for Clients' and Carers' Experiences of an EIS

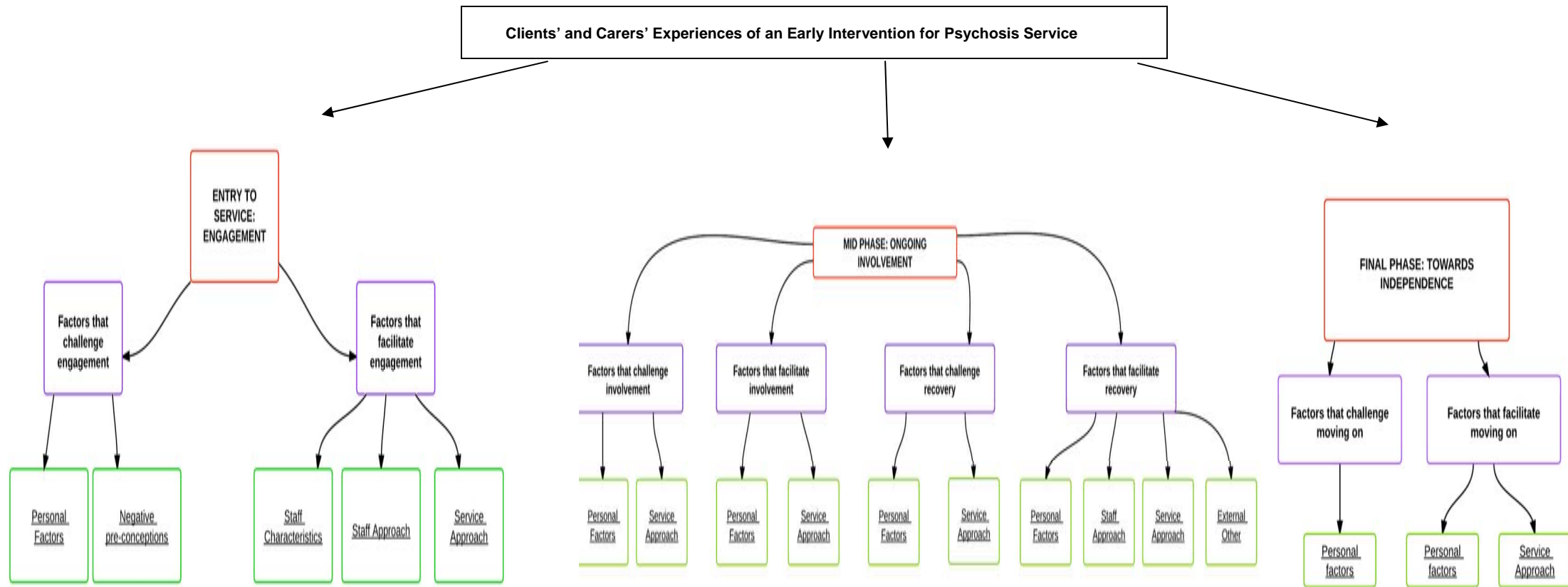
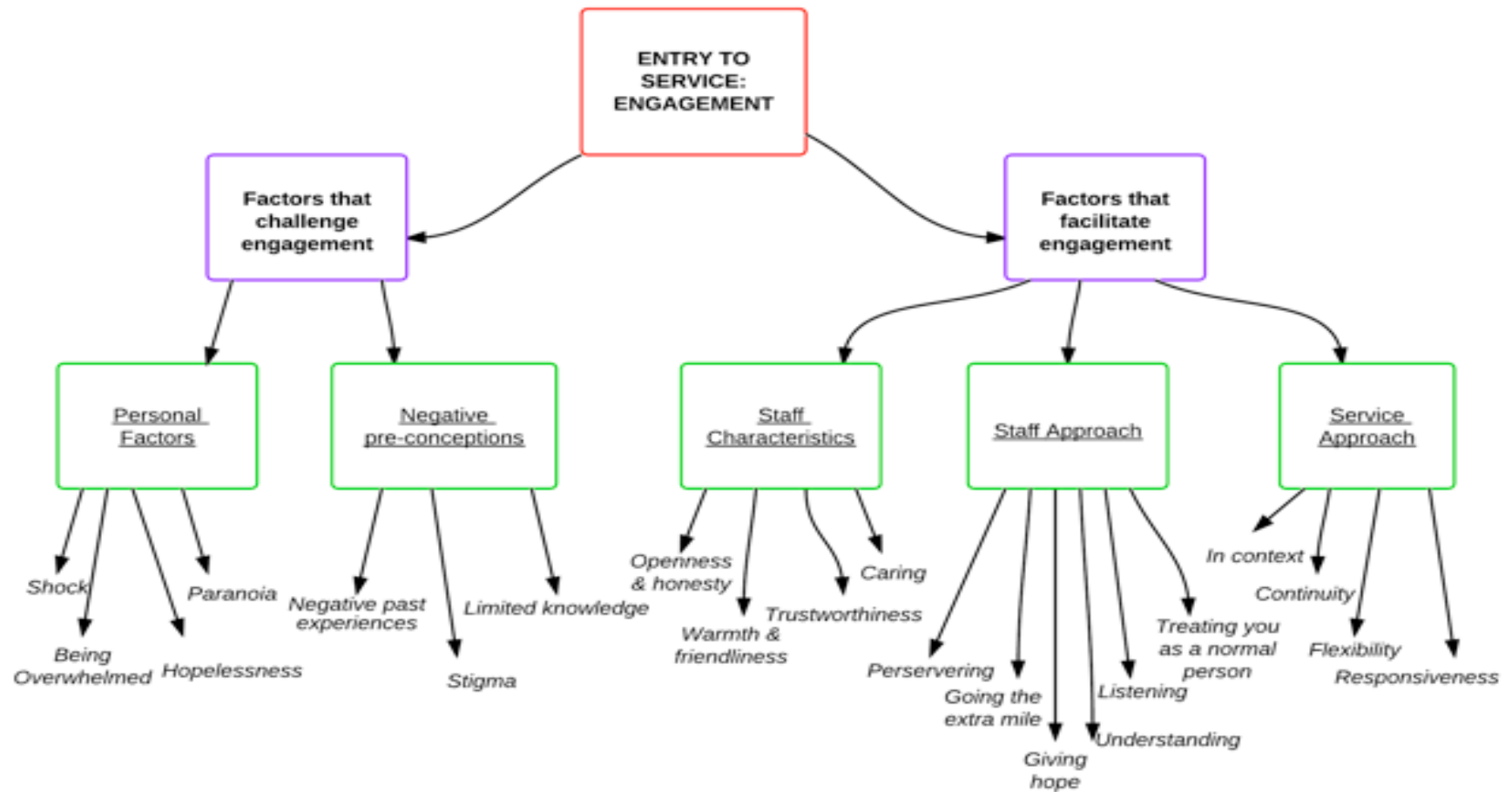


Figure 3.2: Diagrammatic Summary of Core Category, Categories, Sub-Categories and Concepts of Engagement



3.2 CORE CATEGORY: ENTRY TO SERVICE- ENGAGEMENT

This core category encompasses the experiences of participants when they are first introduced to the EIS. This seems to be a complex process in which there appear to be a number of factors which may either hinder or help a person's engagement with the service. Within this core category are two categories: '**factors that challenge engagement**' and '**factors that facilitate engagement**'.

3.2.1 Factors that Challenge Engagement

This category refers to factors which may potentially act as barriers to the person engaging with the EIS. Within this category are the sub-categories: 'personal factors' and 'negative preconceptions'. These sub-categories refer to the participants' current emotional state and/or pre-existing beliefs about mental health services, both of which may result in participants' reluctance to engage with the EIS.

Personal Factors

This sub-category reflects participants' challenging feelings and emotions occurring at the time of their introduction to the EIS, and as a result of their recent experience with psychosis, which may have hindered their engagement. There are four concepts within this sub-category: '*shock*', '*being overwhelmed*', '*hopelessness*' and '*paranoia*'.

Shock

This concept refers to the suddenness and unexpectedness of the episode of psychosis. Many participants spoke of their lack of understanding about what was happening and resultant sense of shock and disbelief at their situation.

Clients' Examples of '*Shock*':

Caddell: "*It was like a bomb had dropped on the family. We didn't know what had happened*".

Rhiannon: "*It had come on me so suddenly. I didn't know what was happening to me at the time. I hadn't got a clue*".

Carers' Examples of 'Shock':

Rebecca: *"The whole thing was out the blue, totally out the blue, and for her to be ill with that type of illness was quite a shock".*

David: *"My wife was psychotic before we even realised. She went so quick. It was almost as if a switch had been flicked. I could hardly believe it".*

Being Overwhelmed

Several participants spoke of being affected deeply by their recent experiences with psychosis. As a consequence, many commented that they were unable to take anything in, or to process the information provided.

Clients' Examples of 'Being Overwhelmed':

Rhiannon: *"I first met her (EIS worker) in a hospital. I didn't know what was what or what was going on. I couldn't take anything in".*

Bryn: *"I didn't know what was happening. I met them (EIS) but I didn't know what things meant or what was really happening to me in some senses. It was all too much".*

Carers' Examples of 'Being Overwhelmed':

Bethan: *"They (EIS) explained who they were but I couldn't take it all in. I couldn't even believe half of what was going on".*

Carys: *"I don't remember how I met them (EIS). There was so much happening. Your mind is pretty overwhelmed with everything that is going on".*

Hopelessness

This concept refers to the participants' belief that nothing could be done to help them. Many spoke of a sense of despair at the situation they found themselves in and conveyed a feeling of hopelessness at finding a way through to recovery.

Clients' Examples of 'Hopelessness':

Aled: *"I was going to kill myself. Even with help from my family I had convinced myself that there was no point in my life".*

Rhiannon: *"I thought the ward were sending me home because they had nothing else to do for me, like, 'We can't cure her, so just send her closer to home'".*

Carers' Examples of 'Hopelessness':

Rebecca: *"I was thinking 'What am I going to do when she comes home?' 'How am I going to be to be at home with her like this?' There was no light at the end of the tunnel".*

Bethan: *"I thought he would be on medication for a while and then, like ordinary illness, get better, but it's not to be that way. I want him back to normal and I know it can't be".*

Paranoia (CL)

This concept refers to participants' distrust of other people and services, and relates only to clients. Many clients expressed a belief, during the initial phases of their introduction to the EIS, that other people, (including those from EIS), were attempting to harm them or their families.

Clients Examples of 'Paranoia':

Dilwen: *"I was thinking bad things about people. I thought they (EIS) were trying to plot against me to take my daughter away from me and things like that".*

Rhiannon: *"I didn't like meeting new people because of my thoughts at the time. I didn't trust anybody. The first time I met Jemma I called her Satan".*

Aled: *"I thought there was nothing wrong with me. The more I was becoming ill, the more I thought everyone was trying to make me bad".*

Negative Preconceptions

This sub-category reflects participants' pre-existing beliefs, opinions and/or prejudices about mental health services, which may also function as barriers to engagement with the

EIS. There are three concepts within this sub-category: ‘*negative past experiences*’, ‘*stigma*’ and ‘*limited knowledge*’.

Negative Past Experiences

Negative past experiences refers to participants’ prior exposure to mental health services (commonly psychiatric in-patient units) and the professionals associated with these. It appeared that many participants had been in situations which were extremely frightening, often evoking a sense of loss of control and powerlessness.

Clients’ Examples of ‘*Negative Past Experiences*’:

Bryn: “*Initially I was a bit wary of everything to do with mental health to tell you the truth, doctors, nurses, the whole caboodle because of my dealings with them in hospital*”.

Rhiannon: “*They restrained me and I was drugged up all the time. Some of the nurses were terrible. They were really bitter and horrible. They took advantage of the fact that you were vulnerable*”.

Carers’ Examples of ‘*Negative Past Experiences*’:

David: “*It looked and felt like a prison. Some of the people were very intimidating and scary. The whole experience was extremely frightening and we didn’t want my wife to stay there*”.

Rebecca: “*In hospital there had been people who had been like ‘We are going to give your daughter this drug, and that drug, and then we will do this if that doesn’t work’. They have a different air about them, they are not very good at putting things across*”.

Stigma

A significant number of participants made references to a sense of shame at having mental health difficulties and/or being involved with mental health services. Indeed, many disclosed their reluctance to be involved and/or inform others of their involvement with psychiatric services, leading to caution about who they shared this information with.

Clients' Examples of 'Stigma':

Bryn: *"It's not nice to have a psychiatric team. I didn't really want to be involved with those kind of services. You just don't know what people will think".*

Caddell: *"My wife wouldn't mind me being involved if it was away from our home town as the people there wouldn't know us. She would rather I didn't go to the local group".*

Carers' Examples of 'Stigma':

Carys: *"When Caddell was in hospital I saw someone that I knew. That made me step back. It put me off ... it might put other people off, they might worry that someone knew them".*

Rebecca: *"I had to ring them (work) and say 'My daughter is in hospital', but I didn't say why or what. People would be like 'Oh, she's a nutter'. I had to be careful who I told".*

Ffion: *"I've only spoken to people briefly. I've really kept it that close. There's not a great understanding of mental health. There's not. People can get a bit frightened, they don't understand".*

Limited Knowledge

This concept refers to participants' lack of knowledge and understanding of the EIS and not knowing what to expect from the service itself. As a consequence, many clients in particular appeared to experience significant levels of anxiety and distress prior to becoming involved, potentially due to previous negative experiences of mental health services.

Clients' Examples of 'Limited Knowledge':

Bryn: *"This was my first time of being involved. I didn't know what to expect. I was just going in totally blind and it was a bit scary".*

Dilwen: *"I didn't have a clue about the service or what they did. That's what I was nervous about ... I remember I was really anxious".*

Carers' Examples of 'Limited Knowledge':

Ffion: *"As soon as you meet them all these things go round in your head, however intelligent you are, irrational things, and you think 'Oh gosh, what's going to happen next? Where are we going?'"*.

David: *"I had no knowledge of the service or anything. I didn't know how it worked or what it was. I didn't even know if they could help"*.

Bethan: *"I didn't even know it existed. I thought that once a person was discharged that was it"*.

3.2.2 Factors that Facilitate Engagement

This category refers to the factors which potentially facilitate participants' engagement with the EIS. Within this category are the sub-categories: 'staff characteristics', 'staff approach' and 'service approach'. These sub-categories refer to participants' positive experiences of the personal characteristics of the staff, the manner in which staff worked with and/or approached working with them, and the way in which the service was delivered which may have facilitated their engagement.

Staff Characteristics

This sub-category reflects the personal qualities, attributes and/or traits of the staff which were perceived by participants as facilitating their engagement with the EIS. There are four concepts within this sub-category: '*openness and honesty*', '*warmth and friendliness*', '*trustworthiness*' and '*being caring*'.

Openness and Honesty

This concept refers to the participants' perception of the staff being transparent, frank and truthful. Many participants indicated that this openness and honesty was valued and it is possible that this transparency may have been an important factor in the establishment of their working relationship.

Clients' Examples of 'Openness and Honesty':

Rhiannon: *"We are very open with each other, me and Jemma. I didn't feel I had to shy away or lie about anything and I knew she would always be straight with me"*.

Bryn: *"They were very open and honest and for me that helped our relationship".*

Carers' Examples of 'Openness and Honesty':

Bethan: *"You knew that she would always be honest with you, even if it was something you didn't really want to hear".*

Rebecca: *"She would always tell you what was happening. She would say 'We are going to be doing such and such and this is why'. I always knew where I was with Jemma".*

Warmth and Friendliness

This concept relates to the amiability and warmth of the EIS staff. Many participants noted the importance of this in promoting positive feelings within themselves and/or making them feel more able to approach staff if needed.

Clients' Examples of 'Warmth and Friendliness':

Aled: *"They just seemed really warm and friendly. It really triggers you off to think happy or be happy".*

Dylan: *"The EIS staff are always friendly, they always smile which makes you feel good".*

Carers' Examples of 'Warmth and Friendliness':

Carys: *"They couldn't be more friendly or easy going. I think that's what makes them so approachable".*

Ffion: *"Jemma is such a warm person. She is professional but there's also that line where she is very approachable and friendly, which made me feel that I could go to her anytime".*

Trustworthiness

Trustworthiness refers to the participants' perception that they were able to place trust and confidence in the EIS staff. Interestingly, many clients reflected on their experiences of mistrust and wariness of mental health professionals during previous service involvement.

Clients' Examples of 'Trustworthiness':

Rhiannon: *"I didn't trust nurses a lot when I was hospital but I trusted Jemma straight away"*.

Bryn: *"Initially I was wary of everything to do with mental health services ... but Jared was able to overcome that. I trusted him, there's a relationship of trust that builds up"*.

Gareth: *"You can trust them, which helps you open up and explain more of your problems"*.

Carers Examples of 'Trustworthiness':

Rebecca: *"Jemma is somebody that you can trust ... I can trust her with the family, with this history and information"*.

Bethan: *"I would trust Josie with my life"*.

Being Caring

This concept relates to the participants' experience of the EIS staff providing support and showing compassion towards them. Several participants made reference to a sense that staff took genuine pleasure in their well-being.

Clients' Examples of 'Being Caring':

Bryn: *"They kept on coming to see me. I felt like someone was actually bothered about what happened to me"*.

Rhiannon: *"She genuinely cares. You can tell when people are only here for a job and you think 'Oh great, it's a chore for you to come here', but it's like she genuinely wants to see me"*.

Carers' Examples of 'Being Caring':

Rebecca: *"She has a fondness for Rhiannon, so it seems to me, she's genuinely happy that she is doing so well".*

Bethan: *"She comes across very caring. She shows that she cares for you ... she's very sympathetic and supportive".*

Staff Approach

This sub-category relates to the manner in which staff worked with and/or approached working with the participants which may have facilitated their engagement with the EIS. There are six concepts within this sub-category: *'persevering'*, *'going the extra mile'*, *'giving hope'*, *'listening'*, *'understanding'* and *'treating you as a normal person'*.

Persevering

Persevering relates to the idea of the steady persistence of the staff. Many participants noted staff members' continual steady efforts, which appeared to withstand discouragement and/or difficulty and were ultimately effective in facilitating engagement.

Clients' Examples of 'Persevering':

Bryn: *"When I first met Jared I wasn't talking at all. He'd just keep come round and we'd sit literally not looking at each other ... but the fact is, he kept coming. He battled through all of that and found a way to make me feel comfortable enough to talk".*

Aled: *"I didn't want help. I was in denial that I was ill. I totally wouldn't see what other people were seeing but they didn't let up. It's their perseverance ... they were determined to get to the bottom of things".*

Carers' Examples of 'Persevering':

David: *"She never stopped coming. Even when Dilwen wasn't saying much she kept trying to speak with her and find a way through".*

Bethan: *“She’s tried to get Brian in so many different constructive things, so many different things she has tried with him ... men’s group, catering class, gym club. This last one he has really taken to”.*

Ffion: *“She’s done things with him, got him on a course, took him here, took him there, tried things that didn’t work, so tried something else. She kept on trying”.*

Going the Extra Mile

Going the extra mile relates to the participants’ perception that the staff would often make more effort or offer more than they were required when working with them. For many participants this appeared to be extremely meaningful.

Clients’ Examples of ‘Going the Extra Mile’:

Rhiannon: *“We went to see some art, just for a day to look at things. I thought it was so nice of her to do that because she really didn’t need to”.*

Dilwen: *“When I was in hospital Joanne went to court for me. I couldn’t believe that that she had done that ... she didn’t have to do it but she did. That meant a lot to our family”.*

Carers’ Examples of ‘Going the Extra Mile’:

Rebecca: *“Because we didn’t have a car, she took us to a Museum Rhiannon wanted to see and I thought how wonderful of her, because she didn’t need to ... she went that extra mile”.*

David: *“I had the mentality that they would do their bit and head for the gate, it’s not their problem out of hours sort of thing ... but Joanne says to contact her. They really care about their work and the people they are looking after”.*

Giving Hope

This concept refers to the positivity of staff regarding clients’ progression and recovery. Many participants made reference to the significance of this approach in the early stages of their difficulties (e.g. whilst in hospital) and commented on the utility of this in making them feel ‘better’ and more positive about their situation.

Clients' Examples of 'Giving Hope':

Rhiannon: *"I thought I was a prisoner in hospital. I thought I was never going to get out, so it was good to hear Jemma saying 'You are going to get better'. It was so good"*.

Dylan: *"We talked a lot about recovery, even at the start ... they always said I was progressing really well. That was good to hear, it made me feel a lot better about things"*.

Aled: *"Anything they come across they've got a way of making you look at it in a different way so things don't look so dark and it makes you feel better"*.

Carers Examples of 'Giving Hope':

Rebecca: *"To have Jemma saying things like 'She will get better' ... that was the biggest thing ever to say to me. Nobody had told me that in hospital"*.

David: *"She came to visit Dilwen in hospital and that used to keep me going ... she always used to talk positively to me and say 'You'll get through this'. She helped me through"*.

Listening

A significant number of participants remarked on their experiences of being listened to attentively, in whatever subject *they* chose, feeling heard and the value that they placed upon that.

Clients' Examples of 'Listening':

Aled: *"He remembers everyone you have talked about. He's like, 'How's so and so?' and you're thinking 'Bloody hell, he actually listens'. He takes the time to remember what you are saying. It blows you away"*.

Bryn: *"We would go out, we would have a damned good chat and anything I wanted to talk about I was always able to talk about. Jared would always listen"*.

Carers' Examples of 'Listening':

Rebecca: *"The listening was wonderful. They provided an ear, someone that you can bounce anything off, anything that was in your mind".*

Bethan: *"The best thing was the listening ... the fact that there was someone willing to listen to you and your troubles".*

Understanding

This concept refers to the approach taken by staff which facilitated participants' in feeling understood and/or that staff were understanding and non-judgemental of their difficulties. Several participants made reference to the notion that the specialist knowledge of the EIS staff may have facilitated this.

Clients Examples of 'Understanding':

Bryn: *"It did take up a fair amount of time but Jared has built up an understanding of me. I feel he understands where I was coming from".*

Gareth: *"I could tell ... he just knew what I was talking about".*

Carers' Examples of 'Understanding':

Ffion: *"It was so good to speak to someone who doesn't judge you, who you know has an understanding ... has that speciality behind them".*

David: *"The most helpful thing is that you are talking to somebody who you feel knows what you are on about and doesn't judge you".*

Bethan: *"My husband was a bit off-ish, he felt more should be done for Brian, but she was very calm. She understood how he felt. I knew she must have seen this before".*

Treating you as a Normal Person

Many participants commented on feeling that the staff treated them with respect and described a sense of being seen as an individual rather than a patient or a number. Several clients remarked on staff members' interest in the lives they had led before their involvement in services.

Clients' Examples of 'Treating you as a Normal Person':

Bryn: *"I feared that I would be considered a bit of a loon, or treated as though I was a bit stupid, but Jared spoke to me like a human being and was interested in the life I had led"*.

Dylan: *"Some people when they are doing their job don't think of the people, but they (the EIS) see you as a person. Jemma really focuses on the individual"*.

Aled: *"He treats you as an individual, not just another number. That's the way you feel with James... he's always on about when I used to go fishing with the boys and surfing"*.

Carers' Examples of 'Treating you as a Normal Person':

Rebecca: *"Rhiannon was treated as a normal person (by the EIS). When we were in hospital she was very much treated like the patient. It was like, we're the professionals you be quiet, sort of thing"*.

Carys: *"They always respect us and treat us as individuals"*.

Service Approach

This sub-category refers to the way in which the service operates, and is delivered, which may have facilitated participants' engagement with the service. There are four concepts within this sub-category: *'in context'*, *'continuity'*, *'flexibility'* and *'responsiveness'*.

In context

In context refers to the provision of support and intervention in the individuals' home environment. Many participants reflected on the importance of the EIS in allowing them to be treated at home, which was their preference, as opposed to being treated in hospital. Some noted that this service approach facilitated the experience being integrated into a real life context.

Clients' Examples of 'In Context':

Bryn: *"The major thing that the EIS allowed me to have was to be treated at home and that is what I really wanted"*.

Aled: *"Ultimately I preferred them coming to my house. When I went to meet the Doctor in hospital all the other people seemed really mad. I didn't want to go in a nuthouse".*

Carers' Examples of 'In Context':

Rebecca: *"Having someone come to your home, instead of going up the hospital made an unbelievable difference ... it made Jemma part of our lives".*

Carys: *"The home visits have been brilliant, to be truthful, because it helps you put it in a normal context ... it just makes it all feel more normal".*

Continuity

This concept relates to the service approach of allocating specific staff members to clients and their families throughout the EIS process. Many participants noted the importance of continuity in developing a positive therapeutic relationship with staff. Others noted the value of that individual knowing their particular story and background.

Clients' Examples of 'Continuity':

Caddell: *"Since the beginning it has been Jared. He knows where I've been and where I am so he's a more useful person to speak with ... it's useful to have a person who has had some continuity with the whole thing".*

Harri: *"It's always been Jemma and I like that. I like having the same person because you build up a relationship with that person".*

Carers' Examples of 'Continuity':

David: *"It takes you a while to build up a new relationship with people. Joanne we have got to know over a lot longer time, so I think we have a good working relationship. It's important to have the same person as much as you are able".*

Carys: *"The lead up into hospital there were so many people you were having to spill the story to and I can remember feeling I didn't want to get engaged ... continuity is a big thing when you are dealing with something like this".*

Flexibility

The concept of flexibility refers to the service approach being adjustable to the needs of the person. Many participants recalled examples of flexibility when arranging locations, times and frequency of appointments.

Clients' Examples of 'Flexibility':

Dylan: *"If the time is not convenient for the appointment then they will go out of their way to change it to suit you".*

Rhiannon: *"She is always saying we can meet wherever I want, for coffee or whatever, instead of meeting at home".*

Gareth: *'They're flexible. They always find a time that suits you'.*

Carers' Examples of 'Flexibility':

Rebecca: *"One of the greatest things was that she wasn't on me like a ton of bricks. She said, 'I'll come and see you everyday if you want me to, or I'll come once a week. It's up to you'".*

David: *"Whenever you make an appointment they always ask if it's convenient. They always say 'If that's too early we can come later'".*

Ffion: *"Jemma always said, 'Let's do our appointments at a time to suit you'. She was always making them at the end of the day so that I could attend and not be worried about asking for time off".*

Responsiveness

This concept relates to the service reacting quickly and effectively to participants' immediate needs, requests and/or emergencies. Indeed, several participants stated that when faced with crisis situations their needs had been addressed immediately.

Clients' Examples of 'Responsiveness':

Caddell: *"The best thing about the service is that when I've needed more I've gotten it. The frequency of the visits has varied depending on the situation, so since I've had a little relapse the frequency has gone up. That has been useful".*

Dylan: *“If you need them they will come straight out and see you and if you really need to see the doctor they will put it all into effect”.*

Harri: *“She listened to what I said about the voices increasing and acted upon it. She got something done about it on that very day”.*

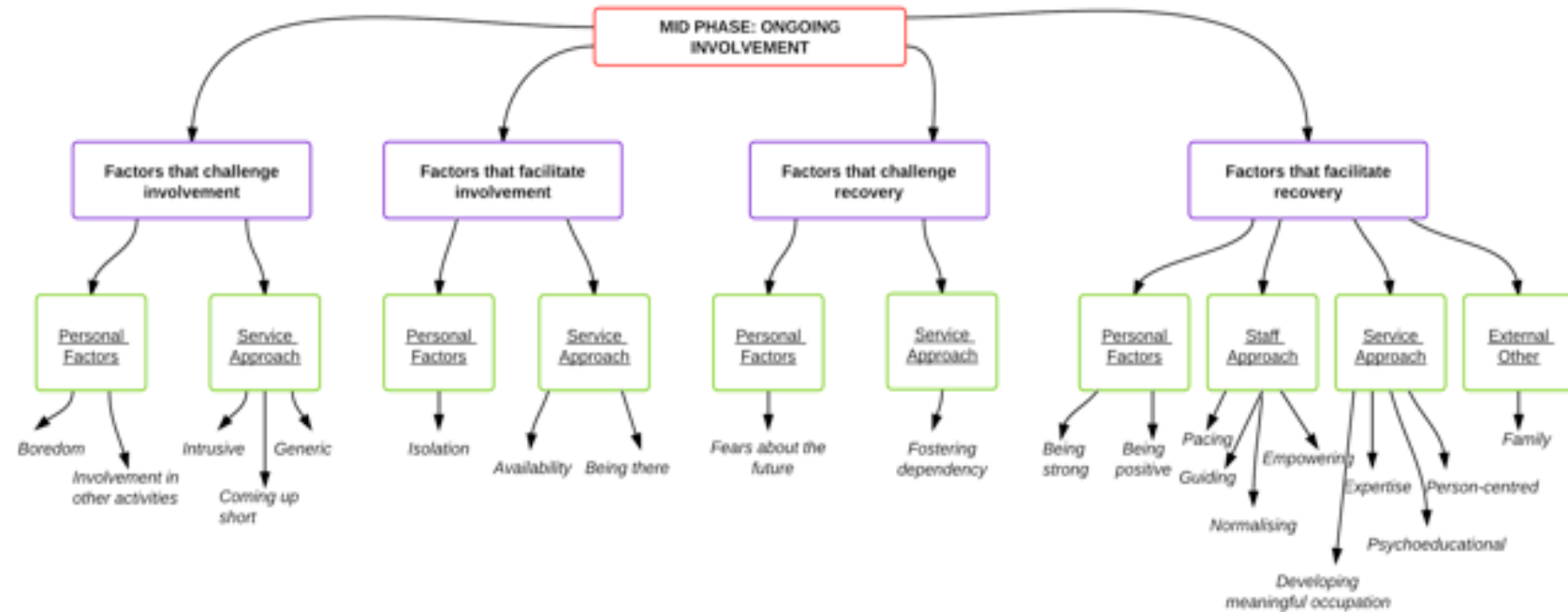
Carers’ Examples of ‘Responsiveness’:

Bethan: *“She acted on what I told her straight away, she brought up somebody who deals with solvent abuse immediately to see Brian ... she acted on it straight away”.*

Rebecca: *“She said that she will get back to me even if it’s on a weekend. I have texted her in an emergency and she has got right back to me”.*

Ffion: *“He went through a dark patch a few weeks ago and she came. I think she was popping in twice a week, and then when he got better she said ‘I’ll come and see you once a fortnight’. She’ll raise her visits when he needs her”.*

Figure 3.3: Diagrammatic Summary of Core Category, Categories, Sub-Categories and Concepts of Ongoing Involvement



3.3 CORE CATEGORY: ONGOING INVOLVEMENT

This core category encompasses the experiences of participants when they are engaged with the service and in the process of recovery. There appear to be a number of factors which may either hinder or help a person's ongoing involvement with the service. Within this core category are four categories: **'factors that challenge involvement'**, **'factors that facilitate involvement'**, **'factors that challenge recovery'** and **'factors that facilitate recovery'**.

3.3.1 Factors that Challenge Involvement

This category refers to factors which may potentially act as barriers to the person remaining involved with the EIS. Within this category are the sub-categories: 'personal factors' and 'service approach'. These sub-categories refer to participants' personal factors (e.g. life circumstances), and the way in which the service was delivered, which may have challenged their ongoing involvement with the EIS.

Personal Factors

This sub-category reflects participants' feelings of dissatisfaction regarding the utility of input from the EIS (at some stages) and their level of engagement in activities outside the service which, in turn, may impact negatively on their involvement. There are two concepts within this sub-category: *'boredom'* and *'involvement in other activities'*.

Boredom

Boredom refers to the participants' sense of tedium at having to cover the same issues and/or questions a number of times. Some reported a reduction in a sense of being able to glean anything new or stimulating from the EIS input.

Clients' Examples of 'Boredom':

Harri: *"She keeps asking the same questions over and over. She'll ask me the same question in three different ways and I think 'We've already done that' ... I felt like I knew most of it"*.

Dilwen: *"I was quite glad when the sessions went to twice a month, because it was getting a bit too much once a week. We were just talking about the same things"*.

Carers' Examples of 'Boredom':

David: *"They were just going over old ground ... a case of coming for a cup of coffee, nothing to report and then going. There didn't seem to be anything new really".*

Carys: *"At times it could be a bit repetitive".*

Involvement in Other Activities

A significant number of participants suggested that engagement in other activities often clashed with their involvement with the EIS, which led to them either reducing the frequency and/or duration of EIS appointments or missing them altogether. Many cited employment (either paid or voluntary) as a significant factor.

Clients' Examples of 'Involvement in Other Activities':

Harri: *"Sometimes we will only meet for about 10 minutes because I'm busy with other stuff, like work and helping with my dad's allotment".*

Dylan: *"I see her every two or three weeks now, that because I'm doing things with the voluntary group and stuff".*

Carers' Examples of 'Involvement in Other Activities':

Bethan: *"On occasions I might miss a week. It depends on my rota in work, because of course I work any day of a week, so I might not see her".*

David: *"I wasn't always there at meetings with my wife and Joanne, it depended on what shift I was working".*

Service Approach

This sub-category refers to the way in which the service operates and is delivered, which may have challenged participants' involvement in the service. There are three concepts within this sub-category: 'intrusive', 'coming up short for carers', and 'generic'.

Intrusive

This concept refers to the invasive nature of the service approach, whereby staff will visit individuals at home, deliver interventions within this environment and often need to know intimate details about their lives. Many participants remarked on the frequency of the visits and indicated these could sometimes feel excessive.

Clients' Examples of 'Intrusive':

Aled: *"At first I didn't like them coming to my house. I knew they had to, but I didn't like it. It was like coming into my personal space"*.

Bryn: *"I think they were there for most nights to make sure I took the medication ... part of me was saying 'I'm never going to escape'. I felt hunted"*.

Carers' Examples of 'Intrusive':

Bethan: *"Sometimes I think it might be a bit too much ... sometimes I think 'It's my day off and I've got to wait for someone'"*.

Carys: *"It felt like it was someone else was prying into your story ... needing to know all about it"*.

Coming up Short for Carers'

This concept refers to the participants' perception that the service did not adequately meet the needs of the carers. Many highlighted the significant levels of stress that were placed on carers, and articulated a need for the provision of specific support for these individuals from the EIS in addition to the care provided to the clients.

Clients' Examples of 'Coming up Short for Carers':

Caddell: *"I think there would be a value in my wife having someone who she could talk to about things and get support. The whole thing does put a lot of stress on her life"*.

Harri: *"I heard on the TV that you should listen to the carers more. I don't think it would hurt to speak with the carers every six months. It's hard for them to deal with too"*.

Carers' Examples of 'Coming up Short for Carers':

Ffion: *"I'm smiling now but two years ago I wasn't smiling ... in the initial stages it was a real worry, and perhaps having someone to offload your worries to might have been useful. It can be a lonely place".*

Carys: *"I wonder if that early on having a meeting just for you (the carer) might have been useful. I think there is a stage where it is harder for you as a carer".*

David: *"Opportunities should be given for carers to talk privately with the EIS. It was difficult sometimes to manage it all".*

Generic (CL)

This concept relates only to clients, and refers to their perception that the service offered a universal blanket approach to all. Many felt that this approach was unhelpful and experienced it as limiting and/or daunting.

Clients' Examples of 'Generic':

Harri: *"She told me about the early intervention team and said 'I'll be with you for three years'. I don't know how I felt about that ... it felt like a hell of a long time and I wasn't sure if I needed all that".*

Dylan: *"When she said about three years for getting back to work and stabilised, I thought 'You can't really say that' ... I think if they just worked with people that would be better than limiting things".*

3.3.2 Factors that Facilitate Involvement

This category refers to factors which may potentially contribute to the person remaining involved with the EIS. Within this category are the sub-categories: 'personal factors' and 'service approach'. These sub-categories refer to participants' engagement in and support from social networks, and also the way in which the service was delivered which may have facilitated their ongoing involvement with the EIS.

Personal Factors

This sub-category reflects participants' lack of engagement in social networks because of their difficulties and/or a perception that others would be unable to understand their experiences. This, in turn, may have facilitated participants' involvement with the EIS as staff provide support and are equipped with the specialist knowledge and expertise which may promote individuals' sense of being understood. There is one concept within this sub-category; *isolation*.

Isolation

Isolation refers to the participants' sense of being cut off or separated from others as a result of the illness. Many commented on the process of attempting to communicate their experience to other people (outside the EIS) and their sense that others were unable to fully understand, which in turn compounded their sense of isolation and separation from valued social networks/support.

Clients' Examples of 'Isolation':

Rhiannon: *"My friends totally forgot about me. I lost a lot of friends through it. I hardly had anyone. I tried ... but they just didn't understand"*.

Harri: *"I was very socially isolated because of it (mental health difficulties). I wasn't involved with people at all"*.

Carers' Examples of 'Isolation':

Rebecca: *"I couldn't call family or church members because none of them had experienced this, they wouldn't have a clue so I couldn't talk to them ... talk about being on your own"*.

Bethan: *"It's a lonely place. You can explain to people, but they don't understand"*.

Service Approach

This sub-category refers to the way in which the service operates and is delivered which may have facilitated participants' involvement with the EIS. There are two concepts within this sub-category: 'availability' and 'being there'.

Availability

This concept relates to the quality of the EIS being at hand if and/or when needed. Many participants commented on the importance of having a staff member's direct telephone number and knowing that they could contact them in the event of crisis situations.

Clients' Examples of 'Availability':

Harri: *"She says if I ever need her I've only got to phone her ... she's only at the end of a phone and I can call anytime"*.

Rhiannon: *"I've always got her number with me and she is always saying whenever you need anything, if things aren't right or in any situation to call"*.

Carers' Examples of 'Availability':

Carys: *"They are always very good and say phone if things are not going well ... don't hesitate to call. I think the most helpful thing is knowing we can contact them easily if we need"*.

Rebecca: *"Jemma always made herself available; she always said to contact her, any time of the day or night"*.

Ffion: *"She says to me frequently, 'I'm at the end of the phone', that I have her number and if I need to speak to her about anything to ring"*.

Being there

Being there refers to the participants' perception that someone was alongside them throughout the process. Many participants made references to the value of simply knowing someone was there for them, even when they were not physically present.

Clients' Examples of 'Being there':

Rhiannon: *"It was like she was always there even when she wasn't ... it was so good just to know that there was someone to turn to"*.

Dilwen: *“It’s just knowing that she is there for you, that you can turn to her when you have a problem”.*

Carers’ Examples of ‘Being there’:

Rebecca: *“If you are in a situation, knowing someone is there for you makes a huge difference. It stops you going over the edge because you could easily if you thought too much about it”.*

Carys: *“You knew there was always somewhere to turn to when you needed help. They were there for you”.*

3.3.3 Factors that Challenge Recovery

This category refers to factors which may potentially act as barriers to the person’s recovery. Within this category are the sub-categories: personal factors’ and ‘service approach’. These sub-categories refer to the participants’ anxieties about the future and also to the way in which the service was delivered which may have challenged their recovery.

Personal Factors

This sub-category reflects the participants’ worries and anxieties regarding the future, specifically concerning the possibility of relapse and their ability to cope, which may have hindered their recovery. There is one concept within this sub-category; *‘fears about the future’*.

Fears about the Future

This concept refers to a sense of fear of the unknown future. Many participants commented on their fears of having to cope alone, the ongoing uncertainty of relapse or whether, indeed, they would recover at all, which in turn appeared to raise anxieties and levels of distress.

Clients’ Examples of ‘Fears about the Future’:

Harri: *“When it ends, it’s going to leave me on my own. I’m a little bit worried that I might need her if things go wrong again and she isn’t going to be there”.*

Dilwen: *"It feels scary thinking about ending and not having that link with them, something close by, just in case it happens again"*.

Caddell: *"I would like to recover, but I don't know how or if I can do that"*.

Carers' Examples of 'Fears about the Future':

Carys: *"I don't know when Jared will withdraw, and what happens then? Do we have their phone number forever? I imagine for a couple of years yet you are going to be on tenterhooks should things deteriorate"*.

Ffion: *"If they stopped now I would worry about what he would do in the future and how I would support him on my own. You worry as a carer about whether what you are doing is right"*.

Service Approach

This sub-category refers to the way in which the service operates and is delivered which may have challenged the participants' recovery. There is one concept within this sub-category; *'fostering dependency'*.

Fostering Dependency

Fostering dependency refers to the apparent reliance of participants upon the service and the perception that they would have been and/or would be unable to cope alone. In particular, several clients' comments suggested that they were mindful of the issue of dependency on the EIS.

Clients' Examples of 'Fostering Dependency':

Rhiannon: *"I would like it to continue in the future, to know that she is still there even when I'm off the service and to stay in touch ... she tells me what I need to do"*.

Bryn: *"In some respect any problems I suffer in my life I unload onto Jared. I've wondered whether there could be a dependency issue"*.

Dilwen: *"I got reliant on other people ... I was dependent on them (the EIS)"*.

Carers' Examples of 'Fostering Dependency':

Rebecca: *"What would have happened if she wasn't there? I don't know what the heck I would have done without her. I really don't".*

Bethan: *"I think now how do people manage without them? I know I couldn't manage without her ... I don't know what I'd do if I didn't have them".*

3.3.4 Factors that Facilitate Recovery

This category refers to factors which the participants appeared to experience as having a positive impact on recovery. Within this category are the sub-categories: 'personal factors', 'staff approach', 'service approach' and 'external other'. These sub-categories refer to the participant's resilience, the manner in which staff worked with and/or approached working with them, the way in which the service was delivered, and influences outside the EIS, which may have facilitated their recovery.

Personal Factors

This sub-category reflects participants' determined attitude and prevailing sense of positivity and hopefulness regarding improvement which, in turn, may have a positive impact on their recovery. There are two concepts within this sub-category: '*being strong*' and '*being positive*'.

Being Strong

Being strong refers to the participants' steadfastness in 'holding it together' and not giving up. Many commented on the importance of being strong for significant others and it is possible that these relationships of responsibility may have strengthened the individuals' resolve to recover and/or belief in recovery.

Clients' Examples of 'Being Strong':

Gareth: *"I had to hold it together ... I've got two children".*

Dylan: *"I didn't give up ... I never gave up".*

Carers' Examples of 'Being Strong':

Rebecca: *"I never broke down. I wasn't crying. I wasn't in a state because I wanted to be as much help to her as I possibly could"*.

Bethan: *"I had to try and be strong for Brian ... even when I didn't feel it"*.

Being Positive

This concept refers to the participants' positive mental attitude towards their recovery. Many reflected on the importance of positive traits within their personality, holding onto the belief that things would improve and focusing on achieving their future goals.

Clients' Examples of 'Being Positive'

Rhiannon: *"I'm a positive person. I've always been like it and I think that helped"*.

Dylan: *"I knew I would get better. I just focused on the future and getting back to the things I wanted to do"*.

Carers' Examples of 'Being Positive':

Rebecca: *"I'm upbeat ... I knew she would get over it, so when I saw her I was always trying to say 'You're going to be alright', 'Everything will be OK'"*.

David: *"I knew things had worked for my wife before (EIS support after 1st episode of psychosis) so I knew that things could work again"*.

Staff Approach

This sub-category relates to the manner in which staff worked with and/or approached working with the participants which may have facilitated their recovery. There are four concepts within this sub-category: *'pacing'*, *'guiding'*, *'normalising'*, and *'empowering'*.

Pacing

This concept refers to the participants' perception that the EIS staff supported them through regulating their progression along the recovery pathway. Many participants commented on the importance of this being at their own pace. However, several

highlighted the importance of staff being aware of the times within this process that they needed to be held, and/or slowed down, and the times when they needed to be pushed.

Clients' Examples of 'Pacing':

Bryn: *"The advice from Jared was you're recovering well and it's a good recovery, but you've still got to take x, y and z easy. You can't rush this".*

Aled: *"They never rushed me. None of this 'Right you've got to do this or that' ... then after a bit of time working with them it was, maybe try doing this and maybe try doing that".*

Carers' Examples of 'Pacing':

David: *"They always took things at our pace, but sometimes when I was talking to them, they were like 'Hang on David, you are getting ahead of yourself, we need to take things one step at a time'"*.

Bethan: *"Sometimes I wish they could get him better faster, but Josie is always saying, 'It's a slow process and you have to be a bit patient and go day by day'"*.

Guiding

Guiding refers to the participants' sense of the EIS staff being able to show them the way; providing advice and/or steering them at times of uncertainty through an unfamiliar process. Many participants commented on a perception that the EIS had guided them onto the 'right' path (to recovery).

Clients' Examples of 'Guiding':

Rhiannon: *"She explained that she would be there to help me ... to guide me through".*

Aled: *"He put me on the right path and helped me stay on it".*

Carers' Examples of 'Guiding':

Rebecca: *"She was like a bright ship on an otherwise very dark journey for me".*

David: *“My wife was depressed and I was concerned but the EIS explained what I needed to do. I felt I had some guidance. They helped me understand what to do and set me on the right road”.*

Normalising

This concept refers to the EIS staff providing information and/or opportunities which enabled the participants to recognise that mental health problems impacted on a broad range of the population and crucially, that they were not alone in experiencing these difficulties.

Clients’ Examples of ‘Normalising’:

Rhiannon: *“It was good to hear that other people have been through similar experiences because you always assume that mental illness is for other people. I saw then that it happens to people of all different ages”.*

Caddell: *“The course (EIS therapeutic group) is a real eye-opener. It was a real eye opener to meet real people who believe really crazy things and all of a sudden my crazy things were less crazy”.*

Aled: *“When you meet other people you work out then that its people from all walks of life that become ill. It’s not just you”.*

Carers’ Examples of ‘Normalising’:

Rebecca: *“When it first happens, you think to yourself ‘Why has this happened?’ ... but she would say ‘My other so and so is improving’ and I realised then that I am not the only person in the world this has happened to”.*

Carys: *“It was helpful when Jared explained about recovery. You realise that there are other people out there recovering”.*

Empowering

This concept refers to the level of choice, influence and control that participants were able to effect over their lives when working with the EIS which, in turn, may have had a positive impact on the development of their confidence in personal responsibility and decision making.

Clients' Examples of 'Empowering':

Dylan: *"These tablets they'd given me (in hospital) was bad for me. I felt like a zombie. I told Jemma that I needed a change and so we worked out a different medication which would help me".*

Bryn: *"I did have issues with taking the medication but it improved when Jared took over ... there was a negotiation as to how much medication I could take and we negotiated a plan to lower the dosage and eventually come off".*

Carers' Examples of 'Empowering':

Carys: *"The EIS has helped us to look out for things that triggered it. It made you feel as if you can manage things by yourselves ... so empowering you".*

David: *"Often I was able to put my input in (to developing relapse prevention plans with the EIS). They said it (his input) was invaluable. I felt I was able to do something useful".*

Service Approach

This sub-category refers to the way in which the service operates and is delivered which may have facilitated participants' recovery. There are four concepts within this sub-category were: 'expertise', 'developing meaningful occupation', 'psycho-educational' and 'person-centred'.

Expertise

This concept relates to the specialist nature of the service. Many participants reflected on their sense that this speciality and subsequent expertise contained within the EIS made staff more able to reach, understand and work effectively with individuals and families, thus potentially helping participants' progress and move forwards.

Clients' Examples of 'Expertise':

Dilwen: *"They were able to reach me when I was puzzled and confused. They have expertise in working with people who think like me".*

Aled: *“My Doctor said to me ‘You need more help than I can give you’ ... the EIS have the expertise and experience in this area. My doctor was right that they could give me the help she couldn’t”.*

Carers’ Examples of ‘Expertise’:

Rebecca: *“When Jemma came, she explained so many things. She has seen it all before, she’s seen everything, what people are going through. She had that expertise which I don’t possess and that was invaluable”.*

David: *“The most helpful thing about the staff is their expertise in the field. You are talking to people who are experts and who understand what you are saying. They have seen it all before”.*

Ffion: *“I think it’s their skills which are so helpful, their knowledge and expertise ... we’re talking about things and she has the answers”.*

Developing Meaningful Occupation

This concept refers to the service approach of encouraging and facilitating clients’ involvement in meaningful activity. Many participants noted the positive impact of engaging in a meaningful occupation. Specifically, this appeared to have a positive impact on participants’ sense of self, levels of social support and daily structure.

Clients’ Examples of ‘Meaningful Occupation’:

Rhiannon: *“Jemma has been helping me with extra things, not just my illness. I went for an interview for some work experience. I thought that was so helpful for getting you back into the swing of things ... it made me feel better about myself”.*

Dylan: *“Jemma introduced me to this group and we go out and help people. I’m always doing stuff with the group now... it gives you confidence and eases you back into society”.*

Aled: *“James was getting me out of the house. He introduced me to a gardening programme and a woodworking shop. I started meeting people and making friends”.*

Harri: *"I wasn't socially involved with people, I was isolated. So, she took me to a men's group and got me doing some volunteering. I think that was probably good for me".*

Carers' Examples of 'Meaningful Occupation':

Rebecca: *"She said 'Come on, you need to do something'. Jemma got her involved in volunteering ... it's good for her to get out the house and start mixing with people again".*

Bethan: *"He used to stay in his bedroom all the time. He never came out ... but he has joined a gym now with Jensen (EIS Worker) which is giving him some structure".*

Psycho-educational

This concept refers to the standardised provision of information to participants about the relevant mental health difficulty and available treatment. Many participants commented that this approach had normalised (see 'normalising' section) their experience and increased their knowledge and understanding of their difficulties, enabling them to cope more effectively, to prevent relapse and to continue on the path of recovery.

Clients' Examples of 'Psycho-educational':

Dylan: *"I think the learning is a good thing. They help you see your signs and what was wrong, so that you can understand how to mend it, not mend it, but progress past it".*

Rhiannon: *"I went to a group too, coping strategies. It was helpful as they were saying how you cope with a stressful situation ... it helps prevent it from ever happening again or at least nips it in the bud".*

Bryn: *"They gave me all the statistics on relapse, and if you're continuously going into hospital then the figures show you quite often end up going back and forth for longer periods. That was useful to know. I didn't want that. It made me focus on what I needed to do".*

Carers' Examples of 'Psycho-educational':

David: *"Last year we were on the road to recovery but she tried to do another course and it started to take its toll ... but because of the course that she did on coping strategies she realised 'I've got to knock it on the head'. She saw it and realised"*.

Carys: *"Jared explained about the stages of recovery. It made me realise that I went through it too, that it's true for the patient and the carer. It helps you realise that it's normal ... so that was helpful"*.

Person-Centred (CL)

This concept refers only to clients' and relates to a service approach which endeavours to put the person's needs and aspirations at the centre of the process. Some clients emphasised the importance of the EIS staff belief that they (the clients) had the ability to make choices for themselves.

Clients' Examples of 'Person-Centred':

Bryn: *"I got on with Jared because for the first time someone asked what I wanted to do about my medication"*.

Aled: *"One of the most helpful things is that they've got so many options for you to look at, and they support you in choosing which of these options you want to do"*.

External Other

This sub category reflects the factors external to the EIS which may have facilitated participants' recovery. There is one concept within this sub-category: *'family'*.

Family

This concept refers to the importance of family in providing support throughout the process. Many participants commented on a sense that they would have been unable to manage or cope without the family system around them.

Clients' Examples of 'Family':

Rhiannon: *"I have a supportive family. I'm lucky in that respect to have people around me. I don't know how people manage on their own".*

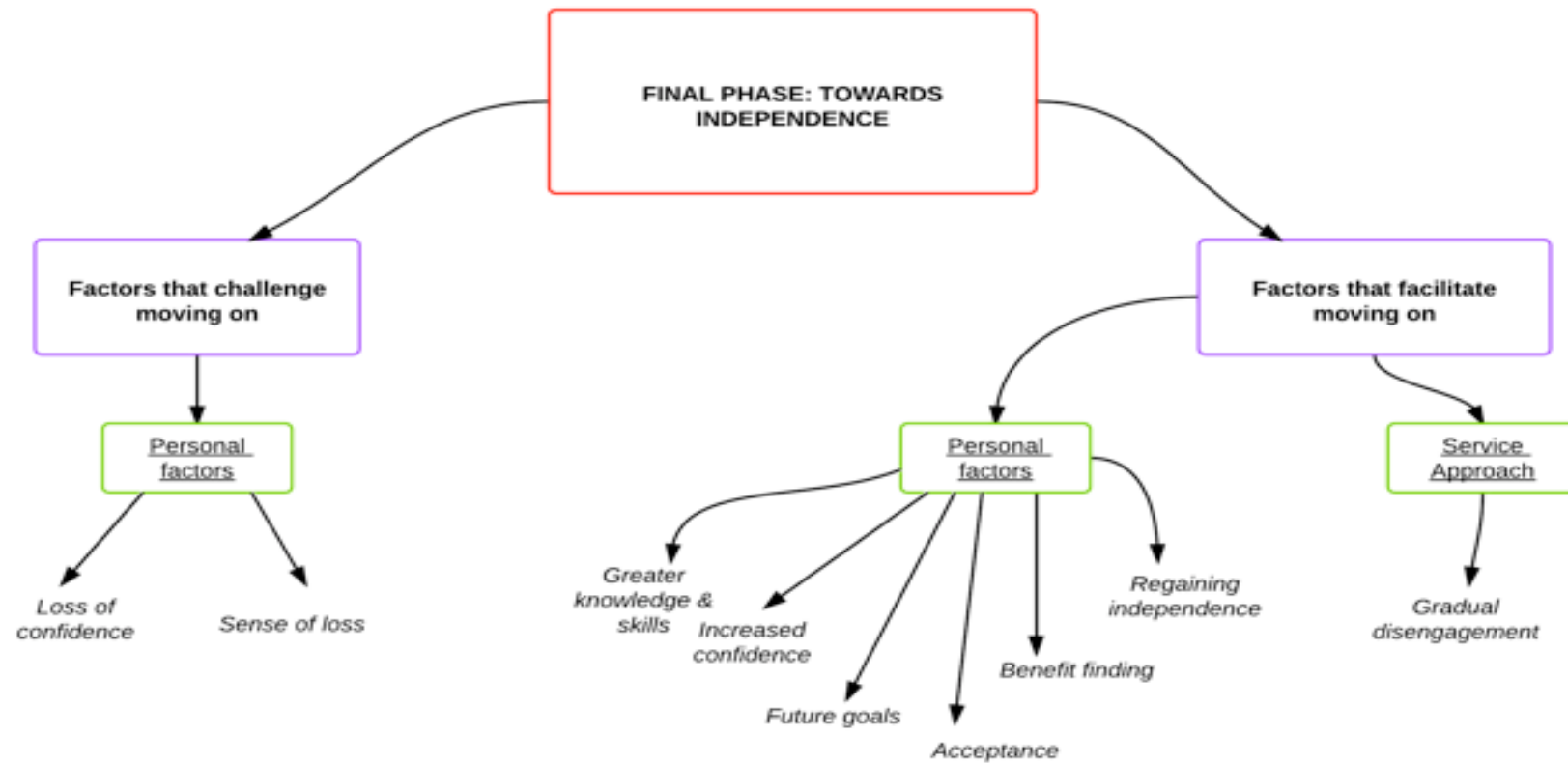
Dilwen: *"My husband is very supportive. I couldn't have coped without him".*

Carers' Examples of 'Family':

David: *"The biggest help for us in addition to the EIS was our family. They were a huge support. We had both sides of our family pulling together".*

Carys: *"My family were there to support us. If we had been on our own it would have been extremely difficult, almost impossible".*

Figure 3.4: Diagrammatic Summary of Core Category, Categories, Sub-Categories and Concepts of Towards Independence



3.4 CORE CATEGORY: TOWARDS INDEPENDENCE

This core category encompasses the experiences of participants when they are entering the final phase of their involvement with the EIS and becoming ready to move on. There appear to be a number of factors which may either hinder or help a person's move towards independence. Within this core category are two categories: '**factors that challenge moving on**' and '**factors that facilitate moving on**'.

3.4.1 Factors that Challenge Moving On

This category refers to factors which may potentially act as barriers to the person moving on from the EIS and becoming independent. Within this category is one sub-category: personal factors. This sub-category refers to participants' feelings and anxieties about disengaging from the EIS and becoming autonomous, which may result in challenging their transition towards independence.

Personal Factors

This sub-category reflects participants' anxieties about moving towards independence. Specifically, this included a lack of confidence in their abilities, and an additional sense of loss at losing the relationship with the EIS staff which may have challenged moving on. There are two concepts within this sub-category: '*loss of confidence*' and '*sense of loss*'.

Loss of Confidence (CL)

This concept relates only to clients and refers to a loss of faith and/or trust in themselves and their own abilities.

Clients' Examples of '*Loss of Confidence*':

Dilwen: "*Sometimes now I think that I can't do anything right, that I'm never going to do anything properly. I can't trust myself*".

Rhiannon: "*Before my breakdown I was quite independent, going about on my own. I think that with my breakdown I got unsure of things*".

Sense of Loss

This concept refers to a sense of sadness and loss at the prospect of losing a person with whom they had developed a close working relationship and shared significant life events. Many participants made reference to a sense that the staff felt like part of the family and/or as a friend.

Clients' Examples of 'Sense of Loss':

Rhiannon: *"She has become like my friend. It's like I will be losing a friend and I don't want to lose a friend. She has seen me through a difficult time"*.

Gareth: *"I guess ending is quite sad because it was nice seeing Jack ... I see him more as a friend than a psychiatric nurse"*.

Bryn: *"I know there's going to come a point when Jared is just too busy with other patients. I think it's something I would miss"*.

Carers' Examples of 'Sense of Loss':

Rebecca: *"I was saying to Jemma the other day, 'I'm going to miss you', because she has become part of the family"*.

Bethan: *"I'll be sad to see Josie go ... she's like my friend and I'll miss her"*.

3.4.2 Factors that Facilitate Moving on

This category refers to factors which may contribute to the person moving towards independence from the EIS. Within this category are the sub-categories: 'personal factors' and 'service approach'. These sub-categories refer to participants' increased knowledge and/or altered attitudes or goals, and also the approach taken by the service when moving towards discharge which may have facilitated moving on.

Personal Factors

This sub-category reflects participants' knowledge, thoughts, feelings and aspirations which may have facilitated their moving on towards independence from the EIS. There are six concepts within this sub-category: *'greater knowledge and skills'*, *'increased confidence'*, *future goals*, *'acceptance'*, *'benefit finding'* and *'regaining independence'*.

Greater Knowledge and Skills

This concept links in with the psycho-educational approach taken by the service and refers to participants' sense of becoming more knowledgeable and skilful in managing their difficulties themselves without EIS intervention. Many noted that they were able to recognise the early symptoms and subsequently intervene to prevent episodes of relapse.

Clients' Examples of 'Knowledge and Skills':

Dylan: *"She showed me what triggered it. So now I know the signs if something is going wrong and what to do".*

Dilwen: *"I learnt a lot. The most helpful thing was CBT, learning how to change the way you think".*

Carers' Examples of 'Knowledge and Skills':

David: *"We drew up a list of warning signs and symptoms. We can now recognise the symptoms so that she does not get to the psychotic stage".*

Carys: *"The EIS helps you realise what has led up to it and prevent it so you keep a look out for those things and do what you can to stop it from happening again".*

Increased Confidence

This concept relates to a sense of an increased faith and belief in their ability to cope with difficulties and/or manage in the future.

Clients' Examples of 'Increased Confidence':

Aled: *"I feel now as though I can handle anything that people throw at me. Whereas before I was petrified of everything, I was petrified of my own shadow".*

Gareth: *"I feel more confident in myself now. I'm working full time which has given me a big boost".*

Carers' Examples of 'Increased Confidence':

Carys: *"It's certainly made you feel you can cope with things a lot better... you feel you can manage things".*

Rebecca: *"I feel more confident because I know what to do now... if this happens I know I need to do this and this".*

Future Goals

This concept refers to participants' hopes and ambitions as they look towards the future. Many reflected on their short and long term future plans which did not involve the EIS, such as supporting their family, entering relationships and returning to work.

Clients' Examples of 'Future Goals':

Aled: *"I can see I'm getting somewhere now. I've got goals. I want to go back to work. I want to pay for my daughter's marriage. There are things I want to do".*

Dilwen: *"I want to get my children sorted in school. Then I want to look for a job and get back into work. I would like to work in a kitchen somewhere".*

Carers' Examples of 'Future Goals':

Rebecca: *"I want her to have as full a life as she can possibly wish and to do all the things she wants to do ... to get a boyfriend and go back to Uni. That's what I would really like for the future".*

Bethan: *"Eventually I'd like him to get his own place, a little part time job, meet somebody, get married and settle down. That's all I want".*

Acceptance

Acceptance refers to the participants' attitude towards their experience and the process of learning to accept themselves, their experiences and difficulties. Many participants appeared to note that this attitude of acceptance had enabled them to move forward.

Clients Examples of 'Acceptance'

Rhiannon: *"I've just got on with things. I just accept it now. I don't blame myself for it, for what happened to me. I drew the short straw and I'm ready to get on with my life now".*

Aled: *"That's just what happened. That's what I think now. I've thought of all the whys, but it didn't get me anywhere".*

Carers' Examples of 'Acceptance':

Ffion: *"Of course I didn't want it to happen, but it did. I can't change it. It's just the way things were ... once we'd realised that, it made it easier somehow".*

Rebecca: *"It happened. You have to move on. You can't let this blight the rest of your life".*

Benefit Finding

This concept refers to the participants finding meaning, identifying positive changes and growth that have occurred as a result of their experience, which appeared to lead to the re-establishment of a positive identity. Such positive effects included a greater ability to empathise with others, less concern about the little things in life and an appreciation of things which were not previously considered important.

Clients' Examples of 'Benefit Finding':

Rhiannon: *"It's definitely changed me. It put things into perspective. I realised life is too short to worry about little things now so I don't worry as much as I used to".*

Dylan: *"It changed me in a lot of ways. I think that I can help people with their problems easier because I've been through a lot of things myself".*

Carers' Examples of 'Benefit Finding':

Carys: *"I think it's made me appreciate everything more. You realise that you can't take things for granted".*

Ffion: *"I felt stronger from just managing. It makes you realise that we're all just human beings and we all seem to moan about silly little things. It has given me a different outlook on that for sure".*

Regaining Independence (CL)

Regaining independence refers only to clients and relates to participants' sense of being more in control of their lives. Many noted that they were not so reliant on the support of the EIS and capable of being autonomous, which was experienced positively in regards to moving on to life after the EIS.

Clients' Examples of 'Regaining Independence':

Dilwen: *"I'm starting to rely on myself again. I can do things on my own and not feel so dependent on the team".*

Rhiannon: *"I don't see Jemma as regularly as I did. It's a good thing knowing you can stand on your own two feet again. You know in yourself you are getting better and you don't need as much support".*

Service Approach

This sub-category refers to the way in which the service operates and is delivered which may have facilitated clients and carers moving on towards independence from the EIS. There is one concept within this sub-category: '*gradual disengagement*'.

Gradual Disengagement

This concept refers to the gradual withdrawal of services over time and orientation towards participants' coping independently. Many participants reflected on the effectiveness of services' withdrawal in an incremental and sensitive manner, which allowed them time to adjust, and provided them with a sense of achievement and progression towards life without the EIS.

Clients' Examples of 'Gradual Disengagement':

Harri: *"In the beginning, it was once a week and then after nine months she said 'I'll meet you once a fortnight now, and then go to once a month when you're ready'. I was happy with that. It gave me time to adjust ... I know it has to end sometime".*

Dilwen: *"In the beginning it was three times a week, then it was two times a week, then for a long time it was once a week and now it's every two weeks. I liked that. I felt like I was on the right track".*

Gareth: *"I'm seeing him a lot less now than when I originally started seeing him. It was once a week, now its once a month. I'm quite happy. I knew it was coming. I understand that every start has an end and these are the final stages".*

Carers' Examples of 'Gradual Disengagement':

Rebecca: *"It was once a week and now it's gone down to once a month because she is doing so well. I feel like we are getting somewhere and that she's slowly handing things back to us".*

Carys: *"It's changed over time, but gradually, so it hasn't been a shock. It was twice weekly at one time, but now it's less. You know that gradually they are stepping down and stepping out".*

3.5 CHAPTER SUMMARY

The overall aim of this study was to gain an understanding of clients' and carers' experiences of an EIS, which would potentially lead to an increase in understanding, and improve service provision. The semi-structured interviews elicited a significant amount of rich, in-depth data and GT was utilised to make sense of participants' narratives. The GT analysis identified three core categories: 'engagement', 'ongoing involvement', and 'towards independence'.

The core category of 'engagement' encapsulates factors that the participants perceived as either hindering or helping the process of becoming involved with the EIS. It appeared that participants' personal factors may have functioned as barriers, whilst the personal characteristics of the EIS staff, the staff and service approach may have facilitated the process of engagement.

The process of 'ongoing involvement' encompasses the participants' experiences of when they are engaged with the service and in the process of recovery. There appeared to be a number of factors which either challenged or facilitated participants' involvement with the EIS, and it transpired that participants' personal factors, and the service approach, impacted both negatively and positively on involvement. Furthermore, there also appeared to be a number of factors which either hindered or helped participants' recovery. The barriers to recovery included personal factors and the service approach. Whilst personal factors, the staff approach, the way the service was delivered and external factors (to the EIS) appeared to facilitate recovery.

Participants also spoke about entering the final phase of their involvement with the EIS and the process of moving on, encapsulated by the core category 'towards independence'. This incorporated factors that either hindered or helped this process. It appeared that solely personal factors appeared to challenge moving on. Whereas personal factors and the approach taken by the service, appeared to contribute to the participants' moving towards independence.

CHAPTER FOUR: DISCUSSION

4.1 CHAPTER OVERVIEW

This chapter provides a review of the results of the study and also a discussion of the main issues in relation to the existing literature. The clinical implications of the study are discussed, followed by a methodological critique and recommendations for future research.

4.2 Review of the Results

The overall aim of this study was to explore clients' and carers' views and experiences of an EIS, including such issues as expectations of the service, engagement, relationships, and recovery. This study revealed rich and interesting themes pertaining to clients' and carers' experiences which were grouped into three **CORE CATEGORIES: 'ENGAGEMENT', 'ONGOING INVOLVEMENT' and 'TOWARDS INDEPENDENCE'**. A multitude of personal, staff and service factors were identified as either hindering or helping the processes of engagement, ongoing involvement and the transition towards independence. The key findings will now be summarised and discussed in relation to the existing literature which was reviewed in Chapter One. For the purposes of continuity and clarity each **CORE CATEGORY** will be presented in emboldened capitals, each **category** will be presented in emboldened lowercase and each sub-category will be presented in underlined text.

4.2.1 ENGAGEMENT

The core category of '**ENGAGEMENT**' encapsulated factors that the participants perceived as either hindering or helping the process of becoming involved with the EIS. It appeared that participants' **personal factors** and **negative preconceptions** functioned as barriers, whilst the **staff characteristics**, **staff approach** and **service approach** facilitated the process of engagement. As the Sainsbury Centre for Mental Health '*Keys to Engagement*' report (1998) suggests, the process of engagement is complex and involves a multitude of factors.

The accounts indicated that the early phase of the psychotic illness was extremely distressing for the participants as they struggled to make sense of, and process, the

experience. Indeed, participants described a myriad of complex feelings and emotions (personal factors) occurring at the time of their introduction to the EIS and as a result of their recent experience (with psychosis) which may have hindered their engagement. Such findings are reflective of the literature regarding the emotional impact of the experience, as the onset of psychosis is reported to be frightening and confusing (Kilkku *et al.*, 2003), to lead to a multitude of challenging feelings and emotions (MacDonald *et al.*, 2005; Patterson *et al.*, 2005; Sanbrook *et al.*, 2003; Sanbrook and Harris, 2003) and to result in individuals struggling to take on board and/or process any new information (Kulhmann *et al.*, 2005). In particular, participants spoke of the shock associated with the suddenness and unexpectedness of psychosis and indicated that they felt deeply affected by their situation. This mirrors literature indicating the overwhelming nature of the experience of FEP for both individuals and their families (Kilkku *et al.*, 2003; Riley *et al.*, 2011; Shore, 2006). Thus, perhaps unsurprisingly, participants' resultant sense of despair (at both this situation and their prospects of recovery) reflect previous research findings regarding individuals' sense of hopelessness in the early stages of mental health difficulties (Barker *et al.*, 2001; Power *et al.*, 2003), and additionally mirror the 'Moratorium' stage of recovery which is 'a time characterised by a profound sense of loss and hopelessness' (Andresen *et al.*, 2006, cited in Shepherd *et al.*, 2008, p. 4). Such findings are also somewhat reminiscent of the widely held societal belief that individuals experiencing psychosis are unable to recover (McGlashan, 1988). Hence, overall, the data obtained in this study appears to support the recommendation that there should be ongoing assessment and planning for co-morbidity (e.g. depression or suicidality) for both individuals and carers (SCMH, 2003).

In addition, client's accounts indicated that the presence of paranoia impacted negatively on their engagement with the EIS. Despite such a finding being consistent with the DSM-IV-TR (APA, 2000) criteria for psychosis (which includes paranoia as one of a specific set of symptoms) and reflective of a typical client presentation to an EIS (as UK EISs are for individuals in the *acute phase* of psychotic illness (McGorry and Edwards, 1997; Pelosi and Birchwood, 2003), it may also support evidence which details clients' generalised distrust and fearfulness of mental health services (Hagan and Nixon, 2011) and indicate the need for EIS professionals to adopt strategies to promote the development of trusting therapeutic relationships.

The participants' accounts also appeared to indicate that the distress caused by the onset of the illness may have been compounded by the realisation that help was needed from services of which they had negative preconceptions (i.e. little knowledge and/or pre-existing negative beliefs and/or experiences). In response to these preconceptions, participants seemed to become increasingly disinclined to engage with the EIS. These findings are consistent with those outlined in Chapter One, which indicate that there is limited understanding by lay people regarding mental health difficulties and/or the services available (McCann *et al.*, 2011; Phelan *et al.*, 1998), and additionally that there is a strong stigma associated with mental health problems (Angermeyer and Matschinger, 2004; Ostman and Kjellin, 2002). Thus, this may provide support for the recommendation of the need for EISs to raise awareness of mental health problems and of the services available (DoH, 2001; SCMH, 2003).

The current study does not provide information regarding other professionals' knowledge of the EIS. However, the participants spoke of having limited understanding of the service prior to their referral which appeared to raise their anxieties and, in turn, create a barrier to their involvement. This *may* suggest that little or no information regarding the condition and the EIS had been disseminated to participants by referring health professionals and that useful information was not accessed by other means (e.g. internet, local health settings). Thus, tentatively, this may reflect some literature which suggests that psychosis and EISs are not well understood by consumers (McCann *et al.*, 2011) and supports the recommendation for the need for service promotion and closer links/partnership working with other agencies (SCMH, 2003).

Furthermore, in the present study, participants also described their negative past experiences of mental health care services as inhibiting their engagement with the EIS. Such findings are reflective of a raft of evidence which documents individuals' negative (e.g. coercive) experiences of mental health and particularly inpatient services (Gorrell *et al.*, 2004; Hagan and Nixon, 2011; Leavey *et al.*, 1997; Leese *et al.*, 1998; Lester *et al.*, 2009; O'Toole *et al.*, 2004; Pinfold *et al.*, 2004; Riley *et al.*, 2011; Stanbridge *et al.*, 2003; Tyson *et al.*, 2001). Thus this clearly provides support for existing policy recommendations regarding the need for further consumer involvement in service evaluation, development and delivery of mental health services (DoH, 2000; Health and Social Care Act, 2001). Therefore, overall, these findings support existing research that

suggests that individuals are often reluctant to engage in mental health services, for what appear to be extremely valid reasons (SCMH, 1998). Consequently, this may indicate that further research exploring the phenomena of 'engagement' in EISs may be beneficial.

However, a number of factors were identified which appeared to increase the likelihood of participants engaging with the EIS. Primarily, participants identified staff characteristics which had supported this process. Such a finding offers support for literature that suggests that professionals' personal qualities, attributes or traits may facilitate the development of a positive therapeutic relationship (Ackerman and Hilsenroth, 2003) which, in turn, is linked to engagement with services (Davies *et al.*, 2009). In particular, participants' identification of specific characteristics mirrored those previously reported by mental health care consumers as crucial in facilitating the therapeutic alliance and/or engagement with services. These included trustworthiness (Hovarth and Greenberg, 1989), openness and warmth (Borg and Kristiansen, 2004; Mohl *et al.*, 1991; Theuma *et al.*, 2007), and being genuinely caring (Borg and Kristiansen, 2004; Lester *et al.*, 2009; O'Toole *et al.*, 2003; Theuma *et al.*, 2007).

A further theme that emerged in terms of factors which facilitated engagement with the service was the manner in which staff worked with and/or approached working with the participants (staff approach). Specifically, participants reported that staff perseverance, dedication to their work and optimism about recovery increased their commitment to remaining with the service. Such findings provide support for evidence which highlights the importance of staff instilling hope (Perkins, 2006) and 'going the extra mile' (Borg and Kristiansen, 2004) in developing a working alliance and determining an individuals' future engagement with mental health services. In particular staff optimism is crucial given that 'finding and maintaining hope' is a key component to the process of recovery (Andresen *et al.*, 2006). Indeed, instilling hope is important given the deleterious impact that psychosis may have on an individual and families' hopes for the future (MacDonald *et al.*, 2005; Patterson *et al.*, 2005) and resultant high risk of suicide for clients (Dutta *et al.*, 2010). Thus, such findings provide support for key recommendations from the Sainsbury Centre for Mental Health Guide to Developing EISs regarding the *style* of working with this particular group e.g. embracing and promoting optimism (SCMH, 2003).

Participants also identified the importance of professionals' skills in active listening and understanding in promoting their engagement. This mirrors research findings concerning consumers' views on the staff approaches which they perceived to be helpful with regards to providing effective support (Collishaw *et al.*, 2007; Garety *et al.*, 2006; McCann *et al.*, 2011; O'Toole *et al.*, 2004; Shepherd *et al.*, 2008; Stanbridge *et al.*, 2003; Theuma *et al.*, 2007) and, additionally, may tentatively support evidence which suggests that feeling unheard and/or judged may act as a deterrent to engagement (Davies *et al.*, 2009).

Furthermore, being treated as a normal person was discussed by the participants as a factor which increased their engagement with the EIS. This supports literature which highlights the importance of individuals being treated respectfully (McCann *et al.*, 2011) and being viewed as being competent in making decisions for themselves (O'Toole *et al.*, 2003). This may also mirror the shift in EISs (in comparison to previous mental health services) towards collaborative working with the type of intervention reflecting the preferences and priorities of the individual clients (SCMH, 2003). Furthermore, this may also reflect the recommendation that there should be less emphasis on diagnosis, as the service is organised around 'diagnostic uncertainty' (DoH, 2001) and more emphasis on the view that mental health difficulties are something that individuals experience transiently, rather than the sum of who they are *per se* (DoH, 2000). This may, in turn, have facilitated the clients being seen as individuals rather than being subject to labelling and/or 'pigeon holing'. Overall, these findings regarding the impact of the staff characteristics and the staff approach on engagement may potentially support the recommendation of Davies *et al* (2009) to consider such factors in the recruitment and/or training of professionals working within these specialist services.

Finally, the participants' accounts indicated there were also ways in which the service operated and was delivered (service approach) that facilitated engagement. Participants spoke of the importance of being treated in context, by a professional who was familiar to them, in increasing the likelihood of their engagement with the team. This is in line with research which indicates consumers' preferences for home treatment (Piat *et al.*, 2008) and continuity of staff (Birchwood *et al.*, 2006; Lester *et al.*, 2009). Furthermore, participants also discussed the value of the service being flexible and responsive to their needs. This mirrors previous research findings regarding user preferences of service

provision (Birchwood *et al.*, 2006; McCann *et al.*, 2011; Naik and Bowden, 2008; O'Toole *et al.*, 2003) and is suggestive of the literature which documents the importance of services being 'on tap', rather than 'on top' e.g. led by the needs of the consumers rather than the service providers (Repper and Perkins, 2003). Thus, this may support recommendations made by the Sainsbury Centre for Mental Health EIS Guidance, which states that individuals should be treated at home wherever possible, that key workers should be allocated rapidly, and that services should be 'accessible, acceptable, engaging and sensitive to the needs of people' (SCMH, 2003, p.29).

4.2.2 ONGOING INVOLVEMENT

The core category of '**ONGOING INVOLVEMENT**' encompassed the factors that the participants perceived as either hindering or helping when they were engaged with the service and in the process of recovery. It appeared that participants' **personal factors** and the **service approach** functioned as both barriers and facilitators to their ongoing involvement. In addition, it appeared that participants' **personal factors** and the **service approach** challenged recovery, whilst **personal factors**, the **staff approach**, the **service approach** and **external other** factors (to the EIS) facilitated recovery. The number and variety of aspects involved with the process of ongoing involvement with the EIS is perhaps unsurprising given the increasingly broad definition of recovery (Anthony, 1993) (in contrast to the previous medical model definition of recovery which focused predominantly on the cessation of symptoms. Indeed, such a broad spectrum of factors, which either facilitate or impede this process, support the qualitative literature regarding survivors accounts of recovery from mental health difficulties (Kelly and Gamble, 2005; Mancini *et al.*, 2005).

The accounts indicated that even when the participants were engaged with the service, there were personal factors (i.e. boredom and involvement with other activities) which could challenge their involvement and cause them to disengage. Certainly, the need for EISs to provide stimulating and timely interventions relevant to the individual's stage of recovery, and at a time convenient to the consumer, is evident in the literature (Birchwood *et al.*, 2006; Naik and Bowden, 2008; O'Toole *et al.*, 2003; SCMH, 2003). Thus, this supports the requirement, as recommended by the Sainsbury Centre for Mental

Health EIS Guidance, for the service to be sensitive and acceptable to the particular needs of the individual (SCMH, 2003).

In addition, participants also discussed a service delivery (service approach) failure to meet the needs of carers as potentially inhibiting their involvement with the EIS. This reiterates similar findings regarding EIS limitations in supporting carers reported elsewhere (Birchwood *et al.*, 2006; McCann *et al.*, 2011; Naik and Bowden, 2008) and as such may potentially reflect a broader theme of the lack of support and/or value for carers by services in general (McCann *et al.*, 2011). Certainly, the findings replicate those outlined in Chapter One which clearly indicate the need for dedicated support for these individuals (carers) (Riley *et al.*, 2011) and cast doubt over whether families receive a sufficient level of support and/or training as recommended by the Mental Health Policy Implementation Guidance (DoH, 2001) and the Sainsbury Centre for Mental Health Guide to Developing EISs (SCMH, 2003). Support for the families and/or carers of individuals with FEP is particularly important given the significant impact of caregiving upon an individual, such as subjective (e.g. psychological reactions such as sadness, grief or loss) and objective (e.g. practical problems such as disruption of family relationships and finances) difficulties, and the vital role of the family in the person's recovery from FEP (Addington, 2007; Pharoah *et al.*, 2010).

Participants' accounts also indicated that there were further ways in which the service operated and was delivered which challenged their ongoing involvement. Although, interestingly, participants' negative accounts of the service as intrusive and generic did not directly replicate those in the literature (as such findings were absent), they may reflect preliminary evidence suggesting that EISs are coercive (Theuma *et al.*, 2007) and too heavily focused upon medication (Penny *et al.*, 2009). However, perhaps the lack of support for these findings is not unexpected and reflects the claim by Lester *et al* (2009) that there is limited qualitative research and/or service evaluation available in this area and an absence of criticism in studies regarding consumers' experiences of NHS services generally (Staniszewska and Ahmed, 1999). Nevertheless, such findings may firstly, support the recommendation that EIS staff should be trained in person centred approaches (DoH, 2010) and secondly, reiterate the call for further *user led* research which may ascertain a more valid picture of services (Staniszewska and Ahmed, 1999).

Whilst participants did not link the potential impact of personal factors, such as isolation (resulting from the illness and a belief that others would be unable to understand their experiences) on their involvement with the service, the findings of isolation and separation from valued social networks as a result of psychosis mirror those in the literature (Kilkku *et al.*, 2003; MacDonald *et al.*, 2005; Sanbrook *et al.*, 2003; Schulze and Angermeyer, 2003). In addition, they may also tentatively be reflective of findings regarding the impact of stigma associated with mental health difficulties on social withdrawal (MacDonald *et al.*, 2005; Mackrell and Lavender, 2004; Ostman and Kjellin, 2002). As evidence highlights the importance of social support throughout this process for both the individual and their family (Hendryx *et al.*, 2009; Sin *et al.*, 2007), the finding of such a theme clearly supports the recommendation that professionals should work both directly to facilitate the individual/family in maintaining and/or developing support networks, and indirectly to reduce the stigma associated with mental health difficulties (DoH, 2001; SCMH, 2003).

Participants' accounts also indicated that there were ways in which the service operated and was delivered which facilitated their involvement (service approach). Participants discussed the importance of the staff being 'at hand' and 'being there' which replicates research demonstrating that staff availability (Birchwood *et al.*, 2006; Collishaw, 2007; Lester *et al.*, 2009; O'Toole *et al.*, 2003; Theuma *et al.*, 2007) and their ability to be alongside individuals throughout their journey (Birchwood *et al.*, 2006), are valuable to consumers of mental health services. Furthermore, such a finding may also provide support for the recommendation that EIS staff should carry lower caseloads (in order to provide the intensive support required to individuals with FEP and their families) (SCMH, 2003) as such an approach may be problematic in, for example, standard CMHT care where professionals are expected to carry upward of 35 cases (DoH, 2002a).

With regard to recovery, the participants identified that there were a number of factors which challenged this process. In particular, they spoke about personal factors such as fears for the future with regard to their anxieties of coping alone, the possibility of relapse or, indeed, whether recovery was possible. Such fears are frequently reported in qualitative literature regarding individuals' recovery from mental illness (Barker *et al.*, 2001) and this may also be reflective of the common myth that recovery from psychosis is not possible (McGlashan, 1988), despite evidence to the contrary (Davidson and

McGlashan, 1997). Therefore, these findings may offer support for the recommendation that EIS's consumers be provided with psycho-education and relapse prevention strategies, alongside an approach which seeks to empower individuals and increase their confidence in managing their difficulties independently (DoH, 2001; SCMH, 2003).

Furthermore, and possibly associated with the aforementioned personal factors, participants also discussed the service approach as fostering dependency and negatively impacting on their perceived ability to cope alone which, in turn, may have affected their recovery. Whilst this finding does not replicate any existing EIS research, it does mirror findings regarding consumers' experiences of decreased functioning as a result of intervention from previous (i.e. not EIS) mental health services (Hagan and Nixon, 2011; Schrank and Slade, 2007). It is disappointing that these effects remain despite recommendations from the SCMH (2003) regarding the EIS's emphasis on empowering the individual. However, it is notable that there were polarised views on the issue of dependence versus independence as a result of EIS intervention (see section 4.3.2 for a further discussion regarding 'independence').

Nevertheless, there appeared to be several factors which participants experienced as having a positive impact on recovery. The personal factors (e.g. being strong and positive) expressed by participants as being helpful to recovery reflect research findings regarding the positive influence of *internal factors* such as a determined attitude, positivity and hopefulness on the pathway to recovery from mental health difficulties (Ralph, 2000). They are additionally reflective of key components within the recovery process - specifically 'finding and maintaining hope' (e.g. believing in oneself, having optimism about the future) (Andresen *et al.*, 2003) and 'awareness' (e.g. the realisation that all is not lost and that a fulfilling life is possible) (Andresen *et al.*, 2006).

It also appeared that several aspects of the way in which staff worked with and/or approached working with participants (staff approach) facilitated their recovery. Participants spoke about the importance of choice, influence and control over their lives in facilitating this process. This supports Andresen *et al.*'s (2003) claim of 'taking responsibility and control' (e.g. feeling in control of one's life) as a key component in the recovery process. It also mirrors research which highlights the centrality of empowerment in the development of an individuals' personal responsibility and skills in

decision making, which, ultimately supports successful recovery from mental health difficulties (Morton *et al.*, 2010; Shepherd *et al.*, 2008).

Participants also identified the importance of professionals helping them to ‘find the way’ and taking recovery at their (the individual’s) pace. This reiterates findings regarding the utility of the professional in providing guidance (Fisher *et al.*, 2004) and locating the individual as the expert in their own recovery (Roberts and Wolfson, 2004). Indeed, evidence suggests that services (/or staff) which treat the client as the expert in this process increase the likelihood of successful recovery (Shepherd *et al.*, 2008).

Additionally, participants acknowledged the value of staff providing information and employing strategies which enabled them to recognise that mental health difficulties impacted on a broad range of the population. Typically, evidence suggests that lay people have limited understanding or knowledge about mental health problems (Phelan *et al.*, 1998). Thus, this finding reflects research which highlights the value of psycho-education and contact with other people who have had similar experiences (e.g. through service user or carer groups) in normalising and/or helping individuals to make sense of the experience and promote recovery (Rethink, 2009). This supports the SCMH (2003) recommendation regarding the provision of psycho-education to clients, carers and families, and additionally highlights the importance of training staff to utilise particular strategies and/or approaches when working with individuals to facilitate recovery (Davies *et al.*, 2009).

Participants’ accounts of the way in which the service operated and was delivered (service approach) indicated that this also facilitated their recovery. Participants experienced the provision of information (about their condition and/or treatment(s) available) by specialists as helpful with regard to increasing their knowledge and understanding of difficulties, which enabled them to cope more effectively. As indicated above, such findings support the literature regarding the importance of psycho-education in promoting recovery (Collishaw, 2007; Fisher and Savin-Baden, 2001) and the need for specialist practitioners in this area (Garety *et al.*, 2006; Lester *et al.*, 2009). As indicated in Chapter One, there are often organisational difficulties in developing and implementing EISs, as some professionals question the need for separate services (Pelosi, 2009). However, these findings indicate the value of specialist practitioners and

may reflect a number of qualitative and quantitative research findings with regards to consumers' preferences of EISs over standard care with respect to meeting their needs (Garety *et al.*, 2006; Jeppensen *et al.*, 2005; O'Toole *et al.*, 2003).

Participants also spoke of the positive impact of being encouraged and enabled to develop meaningful occupation on their recovery. This is suggestive of previous findings which have implied that occupation has a positive influence on an individuals' sense of self, social support and daily structure (Andresen *et al.*, 2003) which, in turn, may promote recovery (Shepherd *et al.*, 2008). Such findings also support Andresen *et al.*'s (2006) claim of 'rebuilding' (e.g. actively working towards a positive identity and setting meaningful goals) as a key element in the recovery process. Participants in this study additionally stated that they valued an approach which placed their needs and aspirations at the centre of the process. This reflects research indicating the importance of services being user-focused (Fisher and Savin-Baden, 2001; O'Toole *et al.*, 2003) and the SCMH (2003) recommendation regarding the provision of an individualised approach in EISs whereby care planning reflects the preferences and priorities of the individual clients.

Finally, the participants also spoke about the impact of external other factors (to the EIS) (e.g. family) on their recovery. This is consistent with existing findings regarding the importance of family/social networks on mental well being and the value of drawing on personal resources (e.g. families) throughout the recovery process (Collishaw, 2007; Hardy *et al.*, 2009).

4.2.3 TOWARDS INDEPENDENCE

Participants also spoke about the final phase of their involvement with the EIS and the process of moving on, encapsulated by the core category '**TOWARDS INDEPENDENCE**'. This incorporated factors that either hindered or helped this process. It appeared that solely **personal factors** challenged moving on, whereas **personal factors** and the **service approach** contributed to the participants moving towards independence.

The participants' accounts appeared to reflect the historical difficulty of individuals moving on and gaining independence from mental health services (Schrack and Slade, 2007). Indeed, the loss of confidence, faith and/or trust in themselves and their own

abilities (personal factors) reported by participants following an episode of psychosis is well documented in the literature (MacDonald *et al.*, 2005; Sanbrook *et al.*, 2003). Such losses may understandably function as a significant barrier to moving on. This, coupled with the fact that psychosis often occurs during a critical period in a persons' development (DoH, 2001), when their sense of self may already be fragile, means that such an experience (psychosis) may serve to deepen these anxieties. This clearly supports the recommendation for empowerment and psychosocial interventions which serve to increase an individual's self belief and capacity for self management (SCMH, 2003).

A further barrier to participants' transition to independence may be the prospect of losing contact with a person with whom they had developed a close working relationship and whom they depended upon. This may be reflective of evidence which suggests that the relationship between consumers and EIS staff is highly valued with regard to emotional and practical support (Birchwood *et al.*, 2006; Collishaw, 2007; O'Toole *et al.*, 2003), and indicative of evidence which suggests that professionals often form an integral part of clients (limited) support network (MacDonald *et al.*, 2005). In addition, as the stress-vulnerability model (Nuechterlein and Dawson, 1984) suggests, psychosis may be associated with a range of stressful life events, such as bereavement (Nuechterlein *et al.*, 1992), thus individuals may be concerned that a further loss of a significant relationship may prove highly stressful and trigger a reoccurrence of the illness. Thus, is it likely that a staged withdrawal from EIS professionals, which acknowledges and works with an individual's fears and feelings of loss at the end of a relationship, alongside the development of supportive relationships with other involved professionals, may help individuals to manage this transition more effectively.

However, the accounts also indicated, as demonstrated in the literature, that a number of personal factors also facilitated an individual moving on from mental health services and becoming independent (Rethink, 2009). Specifically, participants identified the importance of developing greater knowledge, skills and confidence in managing their difficulties in moving towards independence, which is similar to findings previously reported in the literature (Rethink, 2009). Certainly, greater knowledge and understanding about mental health issues serves to enhance personal responsibility (Shepherd *et al.*, 2008).

In addition, participants also discussed their hopes and ambitions for the future (e.g. returning to work, entering relationships and supporting their family) and desire to regain autonomy over their lives. Setting goals is frequently reported in the ‘rebuilding’ stage in the recovery process and a key component of individuals’ move towards independence (Andresen *et al.*, 2006). As such, these findings may provide support for the recommendation that the achievement of ‘normal social roles’ be promoted within the EIS philosophy (SCMH, 2003).

Participants also reported that accepting their experience, finding meaning, and identifying any positive changes and growth that had occurred as a result of the experience, enabled them to move on more successfully. This is reflective of a raft of research which indicates that acceptance of one’s strengths and weaknesses is associated with recovery (Rethink, 2009). It also supports the literature which demonstrates that a key component to the recovery process is the re-establishment of a positive identity which incorporates illness but retains a core positive sense of self (Andresen *et al.*, 2003) and which, in turn, may lead to successful transition and new future prospects.

The service approach of gradual disengagement was also reported by participants to facilitate the process of moving towards independence. Whilst the subject of gradual withdrawal of services over time and orientation towards individuals coping independently does not appear to be well researched, these findings may offer support for the literature which indicates that EIS termination can be challenging for the consumers e.g. individual’s frequent relapse after discharge from the EIS (Bosanac *et al.*, 2010). Thus this potentially highlights the importance of professionals adopting strategies which provide a period of adjustment for individuals’ and families’ and promote a sense of progression towards a life without the EIS.

4.2.4 Reflection of Findings in Comparison with Key Study (Collishaw, 2007)

The participants’ accounts indicated, as identified in the research by Collishaw (2007), that there were a number of factors which may either facilitate or hinder engagement with the EIS. However, it is notable that whilst the current study findings offer partial support for those factors identified in Collishaw’s study as facilitating engagement e.g. the environment being ‘relaxed and informal’, due to the significant difference in the service investigated e.g. exploration of clients experiences of EIS day programme

(Collishaw, 2007) versus EIS provided in the community as per DOH (2001) guidance (current study) understandably there were several differences within this process. For example Collishaw (2007) referred to factors specific to engagement within a group, such as worries about ‘meeting new people’ and ‘taking part in groups’ (Collishaw, 2007: p.70) whereas the current study explored factors which hindered engagement in mental health services at a deeper level, such as the impact of mental illness (e.g. hopelessness, stigma) and the influence of previous experiences of mental health service involvement which led to negative preconceptions or prejudices. Similarly, whilst the findings offer partial support for Collishaw with respect to ‘people’ (Collishaw, 2007: p.70) supporting the process of engagement, the findings of the current study explored this in further depth and identified three separate sub-categories which supported the process of engagement – the staff characteristics (e.g. openness and honesty, trustworthiness), the staff approach (e.g. persevering and giving hope) and the service approach (e.g. in context and flexible).

The accounts in the current study indicated that there were a number of factors which either hindered or helped a person’s ongoing involvement with the service and recovery. Whilst such findings were partially reflective of the findings by Collishaw (2007) which highlighted the importance of ‘features of the staff group’ (e.g. offering practical support and availability) and the ‘containing qualities of the service’ in promoting ‘how the service is experienced day to day’ (Collishaw, 2007: p.70), the current study elaborated further on the sub-categories and *concepts* which both helped and hindered the participants continued involvement and recovery in an EIS which provided a service beyond that of attendance at a group programme on a day-to-day basis. This involved novel sub-categories incorporating personal factors (e.g. boredom and isolation), the staff approach (e.g. pacing and empowering), the service approach (e.g. coming up short and psycho-educational) and external factors (e.g. family).

Finally, the accounts indicated that there were a number of factors which helped or hindered the process of moving on and transition towards independence from the EIS. Such findings regarding the factors which facilitated this process reflected those identified in Collishaw’s (2007) research, such as, increased confidence and future goals. However, the current study also explored factors which challenged the process of moving on, such as a loss of confidence and a sense of loss (of relationships with staff).

It was apparent that factors which may have hindered the process of moving on were not identified in the research by Collishaw (2007).

4.3 CLINICAL IMPLICATIONS

The current study provided an understanding of the aspects of clients' and carers' experiences of an EIS that they perceived as either challenging or facilitating their engagement, ongoing involvement and transition towards independence. The clinical implications of these findings will now be discussed. These aim to facilitate the provision of more effective and user-centred services.

4.3.1 Conducting Regular Audit and Service Evaluation

It may be advantageous to conduct annual audit and/or service evaluations of individual EISs, (e.g. investigating engagement with service, DNA rates, vocational activity and/or clients' and carers' views respectively) and to disseminate the findings widely to other professionals or agencies. This would enable the service to comprehensively review service activity and effectiveness and would promote the understanding of EIS by other services. It might also facilitate the development of a greater understanding of the needs of the population group, which ultimately might lead to service improvements in line with government recommendations, informed by service consumers. Indeed, the NHS is committed to involving clients and carers in the evaluation of mental health services (DoH, 1995; DoH, 1999).

4.3.2 Public Health Promotion Campaigns to Increase Awareness of Mental Health Difficulties

Mental health difficulties are still largely misunderstood by the wider public (Phelan *et al.*, 1998). Thus, further local and national initiatives to increase awareness of mental health difficulties, to highlight organisations that offer support, to promote the importance of seeking help early and to reduce the stigma and discrimination associated with mental health problems are required. It is possible that involvement of clients within these initiatives e.g. telling their stories, may facilitate the normalisation of experiences (Tanskanen, 2011). There may also be a benefit in specific carer driven initiatives which value, support and advocate the rights of carers (Stanbridge, 2003).

4.3.3 Developing Provision of In-patient Mental Health Services

Mental health services and, in particular, in-patient units, appear to be experienced negatively by clients and carers (Quirk and Lelliott, 2001). Indeed, there is a clear indication that they are experienced as disempowering, coercive and unhelpful in terms of an individual's recovery. Thus, there are indications that wider service evaluation and consumer involvement in aspects of the service, such as staff recruitment, training and service development, may be useful.

4.3.4 Promoting Early Intervention for Psychosis Services

It is clear that more needs to be done, strategically and operationally, to promote awareness, access and availability of EISs. This may involve increased resources, health promotion work, closer links with other agencies (see section 4.3.5), and a leaflet/poster for clients and carers detailing EIS, which may be distributed widely across health, education and youth agencies. It is also possible that the use of internet and social networking sites to promote and advertise such services may be advantageous given the target client group population. In addition, a decrease in obstacles to accessing support through changes to service delivery, such as direct telephone access to the EIS for consultation to families and/or professionals (prior to referral to the service) and self referral, may also be beneficial (Tanskanen, 2011).

4.3.5 Providing Training and Education to Other Services

Providing training and education to other services which may be linked with the EIS client group may also be useful. Primarily, this may equip other professionals and agencies that are likely to come into contact with individuals at risk of developing psychosis, such as GPs, schools and CMHTs, with the knowledge to identify psychosis more rapidly, thus reducing treatment delay, which may in turn improve engagement and outcomes (Perkins *et al.*, 2005). In addition, this may also provide other professionals with a greater understanding of the service offered which may enable them to disseminate information about the EIS more effectively to potential clients and their families. This may be important in reducing clients' and/or carers' emotional distress associated with their referral to EIS due to their limited knowledge and understanding of the service and previous potentially negative experiences of mental health services.

These educational provisions could be provided regularly in written and/or verbal formats, such as pamphlets or workshops.

There is also potentially an indication for further training to be provided to ensure that professionals' knowledge and awareness of policies and legislation regarding carers' rights and needs is sufficient, given the significant difficulties that individuals may face in this role.

4.3.6 Recruitment, Training and Supervision of EIS staff

The selection of professionals with particular characteristics to work within mental health services appears important, particularly in services which are organised around the recovery model. It may therefore be advantageous to involve consumers in the development of job descriptions and in the identification of required/desirable core competencies and/or approaches. Additionally, it may also be beneficial to involve consumers on interview panels to further ensure that there is a 'good fit' between the staff and the consumers.

Regular training is central to continuing professional development and, in turn, contributes to effective service delivery (Onyett, 2003). Such training could, for example, be directed towards teaching and/or refreshing skills in developing and maintaining positive therapeutic relationships, person centred planning, family interventions, and the use of diverse and creative methods to maintain individuals' and families' interest when working together intensively over a long time period. There may also be a benefit in providing education regarding problem solving and/or trouble shooting skills to address future concerns and strategies to increase independence, autonomy and decision making skills. Training may also be offered regarding techniques designed to facilitate an effective 'ending' or termination to service involvement with clients and carers (e.g. collaborative planning of the ending in advance, review and reflection on the process) (Vasquez *et al.*, 2008).

Engaging in supervision is another important aspect of maintaining a high standard of service delivery (Onyett, 2003). Supervision should be available to all practitioners, and may be useful in providing professionals with a space to reflect and consider issues, such as working with clients and/or families who may be ambivalent about engaging and/or

experiencing the service as an unwanted intrusion or the application of psychological techniques. Supervision may be provided by the clinical psychologist working within the EIS, or by an appropriately skilled clinician (DoH, 2007).

4.3.7 Providing a Easy-Read Pamphlet for Clients and Carers

Many individuals struggle to process verbally presented information provided by professionals (Ley *et al.*, 1973), particularly at times of stress (Irvine, 2008). Therefore, it may be helpful to develop a pamphlet to be given to all prospective EIS clients and families. This should contain a comprehensive description of the treatments and services offered and the roles of the EIS team members in an appropriate language (National Institute for Health and Clinical Excellence, 2011). This pamphlet should also include information and links to local support groups, third sector and voluntary organisations.

Specific information should also be available within these pamphlets regarding carers' rights to a formal assessment of their needs and how this may be accessed (National Institute for health and Clinical Excellence, 2011).

4.3.8 Offering a Dedicated Carers' Group

Initially it will be important to ensure that a carers' assessment has been completed in order to develop an accurate formulation about an individuals' needs (DoH, 1995). Whilst the provision of individual support for carers may be problematic, due to their relatives' phase of psychosis, issues of consent and confidentiality, the EIS should endeavour to promote the idea that the service is dedicated to providing support for *both* clients and carers. This message should also be more widely disseminated when providing education and training to other services, and on written promotional documents.

It is possible that the provision of a carers' group may be extremely useful in supporting carers, normalising their experiences and moderating the stress associated with their role (Stanbridge, 2003). The group may offer psycho-education, support, and strategies for managing difficult emotions and may benefit from consultation and involvement of carers in the running of such groups (Sin *et al.*, 2007). However, consideration should be given to any factors which may act as barriers to attending, such as timing and/or the venue of the group.

It may also be important to employ outcome measures for such groups in order to evaluate the impact of the intervention(s). However, it is acknowledged that ‘carers are not patients and psychological morbidity may not be an appropriate measure’ (Szmukler *et al.*, 2003, p.417). Thus accordingly, outcome measures may evaluate the:

- carers’ knowledge about the mental health difficulty utilising the *Knowledge on Schizophrenia Illness* (Barrowclough and Tarrier, 1995);
- carers’ coping utilising the *Carers’ Assessment of Managing Index* (Nolan *et al.*, 1995)
- carers’ appraisal of the caring experience utilising the *Experience of Caring Inventory* (Szmuckler *et al.*, 1996).

4.3.9 Bridging the Gap: Managing Transitions

Finally, it is clear that specific work around ‘endings’ should be conducted between the key EIS professional and the client/carer as the EIS begins to disengage and hand over care to the appropriate services. In order to facilitate an effective transition, it is recommended that there should be a meeting between the services involved together with the client and carer to develop a personalised and collaborative transition plan with a planned ending date. However, it may also be beneficial to build in a degree of flexibility throughout this period. It may also be useful for the EIS to focus on building relationships between the clients and relevant services (e.g. CMHTs or GPs) over a period of months prior to discharge, to provide sufficient education regarding the appropriate services to contact when in crisis, and to ensure that users’ expectations regarding CMHTs or GPs availability are realistic (Lester *et al.*, 2012).

4.4 METHODOLOGICAL STRENGTHS AND LIMITATIONS OF THE STUDY

As indicated in Chapter One, relatively few studies have investigated individuals’ experiences of an EIS. Therefore, an in-depth exploration of this phenomenon was appropriate. This study aimed to explore meaning and develop an understanding of clients’ and carers’ experiences of an EIS. A GT methodology was considered appropriate for a study of this issue (Strauss and Corbin, 1990).

The current study focused on the experiences of a relatively small number of clients and carers who were involved with one EIS service in Wales. Inevitably, there are differences between clients and carers engaged with the service, such as clients' diagnosis, length of time involved with the service, or stage of recovery. However, GT methodology is directed towards gaining an understanding of experiences within a certain time and context and, as such, does not aim to provide generalisable results. Nevertheless, there are commonalities between the themes arising from this study and the findings from the literature regarding clients' and carers' experiences of EISs. Thus, it may be acknowledged that there are similar experiences for EIS clients and carers across the UK due to the, largely comparable, service delivery model.

With regard to the sample size, according to Starks and Trinidad (2007) GT studies typically tend to report sample sizes ranging between 10-15 participants. Whilst the overall number of participants involved fell within this bracket, the sample sizes of the two individual groups fell below this number, and were uneven, as there was a greater number of clients ($n=8$), in comparison to carers ($n=5$). In addition, there were a greater number of male client ($n=6$), and female carer participants ($n=4$), who may have had differing experiences to their respective female and male counterparts. It is possible that the use of theoretical sampling may have been advantageous in this respect. However, there appears to be no evidence to suggest that gender has an effect on individuals' perception of an EIS and an in-depth exploration using a larger sample size would have been problematic given the time constraints inherent in completing research for an academic award. Nevertheless, the sample size may be considered a limitation of the research, as the generalisability of the findings across EISs could be considered limited.

A purposive sampling method was utilised, which gave a broad range of participants, representative of the heterogeneity of the client and carer population at the EIS. However, the sample comprised participants who were recruited through their EIS care coordinators. Hence, it is possible that staff selected individuals who were less likely to hold critical views and more inclined to reflect the service in a positive manner, particularly as the study was due to contribute to the Local Health Board (LHB) Mental Health 'Intelligent Targets' for service development (Paynter *et al.*, 2011). Additionally, the sample comprised people who were willing to participate in this study, which may have biased the data provided. It is impossible to ascertain whether there were any

significant differences between those who participated and those who chose not to take part. It may be hypothesised that those individuals who chose to take part were motivated by a specific agenda, such as positive or negative experiences which they wished to share, therefore making them a non-representative sample. However, the narratives were diverse and reflected findings of previous studies on clients' and carers' experiences of EISs. Hence, whilst it is possible that this may pose a limitation, in general it appears that self-selection bias has not jeopardised this study's findings.

A further limitation may have been that the study was dependent on participants' retrospective self report. Empirical evidence suggests that retrospective self reports are susceptible to a number of cognitive errors arising from memory and recall strategies (Jobe and Mingay, 1991), which may have been further negatively impacted upon by past or current mental health difficulties and/or pharmacological treatment (Franco, 2009). In addition, it is also possible that their narratives may also have been influenced by social desirability, secondary gain, social stigma and self enhancement (Smyth *et al.*, 2000). Thus, it is recommended that these biases are taken into account when considering the findings.

In addition, it is also notable that the researcher began a clinical placement with the EIS described in the current study after the period of data collection. It is therefore possible that the researcher's placement within the team and developing professional relationships with staff may have influenced the analysis of data (e.g. not wanting to portray members of the team in a negative light). However, this was discussed with the researcher's supervisors, who also provided support in reviewing the data and analysis. The themes that emerged were both positive and negative and largely reflective of the findings within the existing literature. Thus, whilst this potentially could be considered to be a limitation, overall it is not perceived to have compromised the results of the study.

Furthermore, it is possible that there may be some overlap with the research conducted by Collishaw (2007). However, in view of the differences of the services investigated (i.e. EIS day programme versus EIS as indicated by DOH (2001) guidance, (specifically, community care and treatment), data collection methods, participants recruited (e.g. clients *and* carers) and differing research findings, whilst this potentially could be

considered a limitation, overall it is not perceived to have compromised the results of the study.

As outlined in Chapter Two (section 2.4), the researcher adhered to a number of guidelines to ensure the quality and legitimacy of qualitative research (Elliott *et al.*, 1999). These included: owning one's perspective and demonstrating reflexivity (section 2.4.1), situating the sample (section 2.8.5), providing credibility checks with additional analysts (e.g. the researcher's supervisors) to ensure that the results made sense, and grounding themes with participants' quotations to ensure transparency of interpretation (sections 3.2, 3.3, 3.4). However, the researcher opted not to utilise respondent validation because GT incorporates ongoing checking as part of the research process (i.e. through constant comparative analysis), and also because this strategy cannot be accepted as an absolute test of the accuracy of results (Elliott and Lazenbatt, 2005).

4.5 RECOMMENDATIONS FOR FUTURE RESEARCH

This study provides a relatively small scale exploratory investigation into clients' and carers' experiences of an EIS. Hence, there are a number of recommendations for future research which have arisen from the study.

In particular, the findings from this study indicated that participants experienced a number of factors which challenged their engagement with the EIS. It would therefore be useful to investigate this matter further. This may be achieved via the collection of data from individuals' engaged with the EIS using a longitudinal study design which explores engagement via semi-structured interviews and measures investigating recovery style (*Recovery Style Questionnaire (RSQ)*, Drayton *et al.*, 1998), insight (*Insight Scale*, Birchwood *et al.*, 1994), psychoses symptoms (*The Positive and Negative Syndrome Scale*, Kay *et al.*, 1987) and service engagement (*Service Engagement Scale*, Tait *et al.*, 2002). Additionally, given the potential difficulties of accessing critical views from service users (Rose, 2001), it may be useful for such a study to be user-led in order to gain a more valid picture of services. Such research may be particularly important as engagement with services is critical in enabling the provision of interventions which may shorten an individual's DUP and facilitate recovery (Perkins *et al.*, 2005).

With regard to further research involving carers, many participants mentioned that they would have benefited from dedicated support and intervention. Therefore, future research could explore the development and evaluation of a support group for carers of individuals involved with an EIS.

As the study employed solely a qualitative methodology, the collection of quantitative data within EIS provision could help to validate the findings. For example, data on academic and vocational opportunities, and familial and/or peer relationships, could provide useful measurements on outcome, as could the use of psychometric questionnaires, which provide standardised measurements of psychotic symptomatology, such as the *PANSS* (Kay *et al.*, 1987) or subjectively experienced burden using the *Caregiver Burden Inventory* (Novak and Guest, 1989).

Indeed, there is a broad range of research that might usefully be conducted within this area. However, given the lack of clarity over the essential structural and functional elements of an EIS (Verdoux, 2001), the first task needed would be the design of a psychometrically sound programme fidelity rating scale, which would enable the comparison of EISs across different contexts. Further, wider scale explorations could then involve qualitative explorations of differing service models for managing FEP, such as early psychosis detection and prevention programmes, the experiences of EISs within diverse cultures, and exploratory qualitative studies investigating the experiences of individuals who play an important role alongside those experiencing FEP, such as mental health professionals, siblings or peers. This may help to develop an understanding and knowledge about the full trajectory of psychosis. In addition, it may also be useful to conduct RCTs to investigate the effectiveness and efficacy of the early intervention paradigm applied across a broad range of disorders in order to establish whether any gains achieved by the EIS are maintained and, if not, how this may be achieved.

Finally, the replication of this current study in other EISs across the UK, would help to validate the findings on a national scale and establish the generalisability of the developing model to other settings.

4.6 CONCLUSIONS

EISs are a relatively recent mental health service provision, with the remit of providing care and intervention to individuals with a first presentation of psychotic symptoms or during the first three years of psychotic illness and their families. The impact of psychosis on the individual and their family can be devastating. Research suggests that individuals with FEP are at a high risk of suicide, whilst caregivers may be prone to experiencing feelings of hopelessness and depression.

Whilst there has been a plethora of quantitative research investigating the effectiveness of this service delivery model, in terms of variables as a reduction in hospital admissions and psychotic symptomatology, little qualitative research has explored what it is *like* to be supported by an EIS.

The current study aimed to explore clients' and carers' experiences of an EIS, including areas such as expectation of the service, engagement, relationships and recovery. It aimed to bridge a gap in the existing evidence base, and accessed individuals' experiences of the service by conducting in-depth interviews with eight clients and five carers (total n=13) and employing GT to make sense of the data.

The study highlighted a multitude of personal, staff and service factors which were perceived as either hindering or helping the processes of engagement, ongoing involvement and the transition towards independence.

Some of these findings reflected previous findings pertaining to the literature regarding EISs and clients' and carers' views, experiences and satisfaction with such services. However, there were several new findings and a number of clinical and research implications arising from the study. The clinical implications relate to facilitating more effective EIS provision by promoting awareness of mental health and EISs, providing training to EIS's staff and allied professionals and encouraging the delivery of interventions targeted specifically at carers. The implications for future research include the need to investigate consumers' engagement and/or non-engagement with EISs, the need to further explore the experiences of individuals who play an important role alongside those experiencing FEP, such as mental health professionals, siblings or peers,

the use of quantitative methodology to validate the findings, and the replication of the study and comparison with other

REFERENCES

- Ackerman, S. & Hilsenroth, M. (2003). A review of therapist characteristics and techniques positively impacting the therapeutic alliance. *Clinical Psychology Review*, 23, 1-33.
- Addington, J. (2007). The promise of early intervention. *Early Intervention in Psychiatry*, 1, 294-307.
- Addington, D., Addington, J. & Maticka-Tyndale, E. (1993). Assessing depression in schizophrenia: the Calgary Depression Scale. *British Journal of Psychiatry*, 163, 39-44.
- Addington, D., Addington, J. & Patten, S. (2007). Relapse rates in an early psychosis treatment service. *Acta Psychiatrica Scandinavica*, 115, 126-31.
- Addington, J., Coldham, B. & Jones, B. (2003). The first episode of psychosis: the experience of relatives. *Acta Psychiatrica Scandinavica*, 108, 285-289.
- Addington, J., Collins, A., McCleery, A. & Addington, D. (2005). The role of family work in early psychosis. *Schizophrenia Research*, 79, 77-83.
- Addington, J. & Gleeson, J. (2005). Implementing cognitive behavioural therapy for first episode psychosis. *British Journal of Psychiatry*, 18, 72-76.
- Addington, J., Leriger, E. & Addington, D. (2003). Symptom outcome one year after submission to an early psychosis program. *Canadian Journal of Psychiatry*, 48, 204-207.
- American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders (4th ed, text revision, DSM-IV-TR)*. Washington, DC: American Psychiatric Association.
- Andresen, R., Caputi, P. & Oades, L. (2006). Stages of recovery instrument: development of a measure of recovery from serious mental illness. *Australian and New Zealand Journal of Psychiatry*, 40, 972-980.
- Andresen, R., Oades, L. & Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37, 586-594.
- Angermeyer, M. & Matschinger, H. (2004). The stereotype of schizophrenia and its impact on discrimination against people with schizophrenia: results from a representative survey in Germany. *Schizophrenia Bulletin*, 30, 1049-1061.
- Anthony, W. (1993). Recovery from mental illness: the guiding vision of mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16, 11-23.

- Appleby, L. (2007a). *Breaking down barriers: the clinical case for change*. London: Department of Health.
- Askey, R., Gamble, C. & Gray, R. (2007). Family work in first-onset psychosis: a literature review. *Journal of Psychiatric and Mental Health Nursing*, 14, 356–365.
- Barker, S., Lavender T. & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health*, 10, 199-212.
- Baronet, A. (1999). Factors associated with caregiver burden in mental illness: A critical review of the research literature. *Clinical Psychology Review*, 19, 819-841.
- Barrowclough, C. & Tarrier, N. (1995). *Families of schizophrenic patients: cognitive behavioural intervention*. London: Chapman and Hall.
- Bertelsen, M., Jeppesen, P., Petersen L., Thorup, A., Ohlenschlaeger, J., Le Quach, P., *et al.* (2008). Five-year follow-up of a randomized multicenter trial of intensive early intervention vs standard treatment for patients with a first episode of psychotic illness. *Archives of General Psychiatry*, 65, 762–71.
- Birchwood, M., Bryan, S., Jones-Morros, N., Kaambwa, B., Lester, H., Richards, J., *et al.* (2006). *EDEN: Evaluating the development and impact of early intervention services (EIS's) in the West Midlands: a report for the NHS service delivery and organisation national R & D programme*. Retrieved 12 November 2011 from http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1304-042_V01.pdf
- Birchwood, M., Smith, J., Drury, V., Healy, J., Macmillan, F. & Slade, M. (1994). A self-report Insight Scale for psychosis: reliability, validity and sensitivity to change. *Acta Psychiatrica Scandinavica*, 89, 62-67.
- Birchwood, M., Todd, P. & Jackson, C. (1998). Early intervention in psychosis: the critical period hypothesis. *British Journal of Psychiatry*, 172, 53-59.
- Bird, V., Premkumar, P., Kendall, T., Whittingson, C., Mitchell, J. & Kuipers, E. (2010). Early intervention services-cognitive behavioural therapy and family intervention in early psychosis: systematic review. *British Journal of Psychiatry*, 197, 350-356.
- Borg, M. & Kristiansen, K. (2004). Recovery-oriented professionals: helping relationships in mental health services. *Journal of Mental Health*, 13, 493–505.
- Bosanac, P., Patton, G. & Castle, D. (2010). Early intervention in psychotic disorders: faith before facts? *Psychological Medicine*, 40, 353-358.
- Brown, M. (2007). *Qualitative methodologies: ethnography, phenomenology, and grounded theory*. Retrieved 2 February 2012 from <http://www.brown.uk.com/teaching/qualitativepostgrad/handout.pdf>

- Cabral, R. & Chaves, A. (2010). Multi-family group intervention in a programme for patients with first episode psychosis: a Brazilian experience. *International Journal of Social Psychiatry*, 56, 527-552.
- Callaly, T., Ackerly, C., Hyland, M., Dodd, S., O'Shea, M. & Berk, M. (2010). A qualitative evaluation of a regional early psychosis service three years after its commencement. *Australian Health Review*, 34, 382-385.
- Canadian Mental Health Association (2000). *An Introduction to Early Psychosis Intervention: Some relevant findings and emerging practices*. Ontario: Canadian Mental Health Association.
- Cantwell, R., Brewin, J., Glazebrook, C., Dalkin, T., Fix, R., Medley, I. & Harrison, G. (1999). Prevalence of substance misuse in first-episode psychosis. *British Journal of Psychiatry*, 174, 150-153.
- Carlsson, A. (1988). The current status of the dopamine hypothesis of schizophrenia. *Neuropsychopharmacology*, 1, 179-186.
- Carpenter, W. & Strauss, J. (1991). The prediction of outcome in schizophrenia: Eleven year follow-up of the Washington IPSS cohort. *The Journal of Nervous and Mental Disease*, 179, 517-525.
- Catts, S., O'Toole, B., Carr, V., Lewin, T., Neil, A., Harris, M., *et al.* (2010). Appraising evidence for intervention effectiveness in early psychosis: conceptual framework and review of evaluation approaches. *Australian and New Zealand Journal of Psychiatry*, 44, 195-219.
- Chen, E. (1999). Early intervention in schizophrenia patients –rationale for its implementation and practice. *Hong Kong Medical Journal*, 5, 57-62.
- Chen, F. & Greenberg, J. (2004). A positive aspect of caregiving: the influence of social support on caregiving gains for family members of relatives with schizophrenia. *Community Mental Health Journal*, 40, 423-445.
- Cheng, F., Kirkbride, J., Lennox, B., Perez, J., Masson, K., Lawrence, K., *et al.* (2011). Administrative incidence of psychosis assessed in an early intervention service in England: first epidemiological evidence from a diverse, rural and urban setting. *Psychological Medicine*, 41, 949-958.
- Chua, S. & McKenna, P. (1995). Schizophrenia – a brain disease? A critical review of abnormalities of structural and functional cerebral abnormality in the disorder. *British Journal of Psychiatry*, 166, 563-582.
- Collishaw, H. (2007). *Clients' experiences of an early intervention service for psychosis*. Unpublished Doctoral Thesis, Cardiff University.

- Craig, T., Bromet, E., Fennig, S., Tanenberr-Karantm M., Lavelle, J. & Galambos, N. (2000). Is there an association between duration of untreated psychosis and 24-month clinical outcome in a first-admission series? *American Journal of Psychiatry*, 157, 60-66.
- Craig, T., Garety, P., Power, P., Rahman, N., Colbert, S., Fornells-Ambrojo, M., *et al.* (2004). The Lambert early onset (LEO) team: randomised controlled trial of the effectiveness of specialized care for early psychosis. *British Medical Journal*, 329, 1067-1069.
- Critical Appraisal Skills Programme (2001). Retrieved 10 September 2011 <http://www.casp-uk.net/>
- Crow, T., MacMillan, J. & Johnson, A. (1986). A randomised controlled trial of prophylactic neuroleptic treatment. *British Journal of Psychiatry*, 148, 120-127.
- Cullberg, J., Levander, S., Holmqvist. R., Mattsson, M. & Wieselgren, I. (2002). One-year outcome in first episode psychosis patients in the Swedish Parachute project. *Acta Psychiatrica Scandinavica*, 106, 276–285.
- Culberg, J., Mattison, M. & Levander, S. (2006). Treatment costs and clinical outcome for first-episode schizophrenia patients: a 3-year follow-up of the Swedish ‘Parachute Project’ and two comparison groups. *Acta Psychiatrica Scandinavica*, 114, 274-281.
- Data Protection Act (1998). *Office of Public Sector Information*.
- David, A., Buchanon, A. & Reed, A. (1992). The assessment of insight in psychosis. *British Journal of Psychiatry*, 161, 599-602.
- Davidson, L. & McGlashan, T. (1997). The varied outcomes of schizophrenia. *Psychiatric Services*, 57, 642-645.
- Davidson, L. & Roe, D. (2007). Recovery from serious mental illness: one strategy for lessening confusion plaguing recovery. *Journal of Mental Health*, 16, 459–470.
- Davies, R., Shocolinsky-Dwyer, R & Mowatt, J. (2009). *Effective involvement in mental health services: assertive outreach and the voluntary sector*. Bristol: Mind.
- Deegan, P. (1996). Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 19, 91-97.
- de Haan, L. (2002). Priorities and satisfaction on the help needed and provided in a first episode of psychosis: a survey in five European family associations. *European Psychiatry*, 17, 425-433.
- de Haan, L., van der Gaag, M. & Wolthaus, J. (2000). Duration of untreated psychosis and the long-term course of schizophrenia. *European Psychiatry*, 15, 264-267.

de Haan, L., van Raaij, B., van den Berg, R., Jager, M., Houwelinh, P., Stockmann, M., *et al.* (2001). Preferences for treatment during a first psychotic episode. *European Psychiatry*, 16, 83-89.

Del Busso, L. (2004). Sharing power in the research process: interviewing young people in the looked after system. *Clinical Psychology*, 44, 7-9.

Department of Health (1995). *Building Bridges: A Guide to Arrangements for Inter-agency Working for the Care and Protection of Severely Mentally Ill People*. London: Department of Health.

Department of Health (1995). *Carers (Recognition and Services) Act*. Retrieved 14 February 2013 from <http://www.legislation.gov.uk/ukpga/1995/12/contents>

Department of Health (1998). *Modernizing Mental Health Services*. London: Department of Health.

Department of Health (1999). *The National Service Framework for Mental Health*. London: Department of Health.

Department of Health (2000). *The NHS Plan: A Plan for Investment. A Plan for Reform*. London: Department of Health.

Department of Health (2001). *Mental Health Policy Implementation Guide*. London: Department of Health.

Department of Health (2001). *Health and Social Care Act (2001)*. Retrieved January 11 from <http://www.legislation.gov.uk/ukpga/2001/15/contents>

Department of Health (2001b). *Mental Health National Service Framework (and NHS Plan) Workforce planning, education and training, underpinning programme: adult mental health services. Final report by the Workforce Action Team*. London: Department of Health.

Department of Health (2001b). *Family Matters: counting families in*. London: Department of Health.

Department of Health (2002). *Improvement, Expansion and Reform – the Next 3 years: Priorities and Planning Framework 2003-2006*. Retrieved 1 January from http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4008430&chk=IXp8vH

Department of Health (2002a) *Community Mental Health Teams: Policy Implementation Guide*. London: Department of Health.

Department of Health (2006a). *Our Health, Our Care, Our Say*. London: Department of Health.

Department of Health (2007). *A guide to Postgraduate Speciality Training in the UK. The Gold Guide*. London: Department of Health.

Department of Health (2007a). *Commissioning framework for health and well-being*. London: Department of Health.

Department of Health (2010). *Personalisation through person centred planning*. London: Department of Health.

Dodgson, G., Crebbin, K., Mitford, E., Pickering, V., Brabban, A. & Paxton, R. (2008). Early intervention in psychosis service and psychiatric admissions. *The Psychiatrist*, 32, 413–416.

Draper, A. (2004). The principles and application of qualitative research. *Proceedings of the Nutrition Society*, 63, 641-646.

Drayton, M., Birchwood, M. & Trower, P. (1998). Early attachment experience and recovery from psychosis. *British Journal of Clinical Psychology*, 37, 269-284.

Dutta, R., Murray, R., Hotopf, M., Allardyce, J., Jones, P. & Boydell, J. (2010). Reassessing the long-term risk of suicide after a first episode of psychosis. *Archives of General Psychiatry*, 67(12), 1230-1237.

Edwards, J., Maude, D., McGorry, P., Harrigan, S. & Cocks, J. (1998). Prolonged recovery in first-episode psychosis. *British Journal of Psychiatry*, 172(33), 107-116.

Edwards, J. & McGorry, P. (2002). *Implementing early intervention in psychosis*. London: Martin Dunitz.

Elliott, M. (1996). Impact of work, family and welfare receipt on women's self esteem. *Social Psychology Quarterly*, 59, 80-95.

Elliott, R., Fischer, C. & Rennie, D. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215–299.

Elliott, N. & Lazenbatt, A. (2005). How to recognize a 'quality' grounded theory research study. *Australian Journal of Advanced Nursing*, 23, 48-51.

Endicott, J., Spitzer, R. & Fleiss, J. (1976). The Global Assessment Scale: a procedure for measuring overall severity of psychiatric disturbance. *Archives of General Psychiatry*, 33, 766-771.

Fedyszyn, I., Robinson, J. & Matyas, T. (2010). Temporal pattern of suicide risk in young individuals with early psychosis. *Psychiatry Research*, 157, 98-103.

Fisher, H., Bordass, E. & Steele, H. (2004). *Siblings experiences of having a brother or sister with first episode psychosis*. Poster presented at the annual conference of the Division of Clinical Psychology, London, United Kingdom.

Fisher, A. & Savin-Baden, M. (2001). The benefits to young people experiencing psychosis, and their families, of an early intervention programme: evaluating a service from the consumers' and the providers' perspectives. *British Journal of Occupational Therapy*, 64, 58-65.

Franco, V. (2009, 8 December). What mental health problems affect memory. *Livestrong.com*. Retrieved 10 December 2011 from <http://www.livestrong.com/article/49695-mental-health-problems-affect-memory/>

Gafoor, R., Craig, T., Garety, P., Power, P. & McGuire, P. (2008). Do the benefits of early intervention treatments persist? 5 year follow up. *Schizophrenic Research*, 98, 83-88.

Gallant, M. & Connel, C. (1997). Predictors of decreased self-care among spouse caregivers of older adults with dementing illnesses. *Journal of Aging and Health*, 9, 373-395.

Garety, P. (2003). The future of psychological therapies for psychosis. *World Psychiatry*, 2, 147-152.

Garety, P., Craig, T., Dunn, G., Fornells-Ambrojo, M., Colbert, S., Rahaman, N., *et al.* (2006). Specialised care for early psychosis: symptoms, social functioning and patient satisfaction. *British Journal of Psychiatry*, 188, 37-45.

Garety, P. & Rigg, A. (2001). Early psychosis in the inner city: a survey to inform service planning. *Social Psychiatry and Psychiatric Epidemiology*, 36, 1-8.

Gilbert, M., Miller, K., Berk, L., Ho, V. & Castle, D. (2003). Scope for psychosocial treatments in psychosis: an overview of collaborative therapy. *Australasian Psychiatry*, 11, 220-224.

Glaser, B., and Strauss, A. (1967). *The Discovery of Grounded Theory*. Chicago: Aldine.

Gorrell, J., Cornish, A., Tennant, C., Rosen, A., Nash, L., McKay, D., *et al.* (2004). Changes in early psychosis service provision: a file audit. *Australian and New Zealand Journal of Psychiatry*, 38, 687-693.

Gross, G. & Huber, G. (1998). Prodromes and primary prevention of schizophrenic psychoses. *Neurology, Psychiatry and Brain Research*, 6, 51-58.

Hagan, B. & Nixon, G. (2011). Spider in a jar: women who have recovered from psychosis and their experience of the mental health care system. *Ethical Human Psychology and Psychiatry*, 13, 47-63.

- Hambrecht, M., Lammertink, M., Klosterkotter, J., Matuschek, E. & Pukrop, R. (2002). Subjective and objective neuro-psychological abnormalities in a psychosis prodrome clinic. *British Journal of Psychiatry*, 181, 30-37.
- Hanssen, M., Bak, M., Bijl, R., Vollebergh, W. & van Os, J. (2005). The incidence and outcome of subclinical psychotic experiences in the general population. *British Journal of Clinical Psychology*, 44, 181-191.
- Hardy, K., Dickson, J. & Morrison, A. (2009). Journey into and through an early detection of psychosis service: the subjective experience of persons at risk of developing psychosis. *Early Intervention in Psychiatry*, 3, 52-57.
- Harris, G., Burgess, P., Chant, D., Pirkis, J. & McGorry, P. (2008). Impact of a specialized early psychosis treatment programme on suicide. Retrospective cohort study. *Early Intervention in Psychiatry*, 2, 11-21.
- Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., Dube, K., *et al.* (2001). Recovery from psychotic illness: a 15 and 25 year international follow up study. *British Journal of Psychiatry*, 178, 506-517.
- Hendryx, M., Green, C. & Perrin, N. (2009). Social support, activities and recovery from serious mental illness: STARS study findings. *The Journal of Behavioural Health Services and Research*, 36, 320-329.
- Henwood, M. (1998) *Ignored and Invisible? Carers' Experience of the NHS Report of a UK Research Survey*. London: Carers National Association.
- Henwood, K. & Pigeon, N. (1995). Grounded theory and psychological research. *The Psychologist*, 12, 115-118.
- Hermann-Doig, T., Maude, D. & Edwards, J. (2003). *Systematic treatment of persistent psychosis (STOPP): a psychological approach to facilitating recovery in young people with first episode psychosis*. London: Martin Dunitz.
- Ho, B., Andreason, N., Flaum, M., Nopoulos, P. & Miller, D. (2000). Untreated initial psychosis: its relation to quality of life and symptom remission in first episode schizophrenia. *American Journal of Psychiatry*, 157, 808-815.
- Hoenig, J. & Hamilton, M. (1966) The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry*, 12, 165-176.
- Hogman, P. & Pearson, G. (1995). *The silent partners: The needs and. experience of people who provide informal care to people with severe mental illness*. London: National Schizophrenia Fellowship Survey.
- Hovarth, A. & Greenberg, L. (1989). Development and validation of the working alliance inventory. *Journal of Counselling Psychology*, 36, 223-233.

- Idstad, M., Ask, H. & Tambs, K. (2010). Mental disorder and caregiver burden in spouses: the Nord-Trøndelag health study. *BMC Public Health*, 10, 516-521.
- Irvine, P. (2008, 13 March). Short term stress can affect learning and memory. *ScienceDaily*. Retrieved 14 December 2011 from <http://l-pawlik-kienlen.suite101.com/how-stress-affects-your-memory-a47649>
- Jackson, C. & Falmer, A. (1998). Early intervention in psychosis. *Journal of Mental Health*, 7, 157-164.
- Jenkins, J.H. (1998). Diagnostic criteria for schizophrenia and related psychotic disorders: Integration and suppression of cultural evidence in DSM-IV. *Transcultural Psychiatry*, 35, 357-376.
- Jeppesen, P., Peterson, L. & Thorup, A. (2005). Integrated treatment of first episode psychosis: effect of treatment on family burden. *British Journal of Psychiatry*, 187, 85-90.
- Jobe, J. & Mingay, D. (1991). Cognition and survey measurement: history and overview. *Applied Cognitive Psychology*, 5, 172-192.
- Johnstone, L. (2000). *Users and abusers of psychiatry: a critical look at psychiatric practice*. (Second edition). London: Routledge.
- Jones, P. B., Bebbington, P., Foerster, A., Lewis, S., Murray, R. & Russell, A. (1993). Premorbid social underachievement in schizophrenia: results of the Camberwell collaborative psychosis study. *British Journal of Psychiatry*, 162, 65-71.
- Kahn, R., Fleischacker, W., Boter, H., Davidson, M., Vergowe, Y., Keet, I., *et al.* (2008). EUFEST study group. Effectiveness of antipsychotic drugs in first-episode schizophrenia and schizophreniform disorder: an open randomised clinical trial. *Lancet*, 371, 1085-1097.
- Kane, J. & Marder, S. (2005). Schizophrenia: somatic treatment. In B. Sadock & V. Sadock (Eds.) *Comprehensive textbook to psychiatry* (pp.1467-1476). New York: Lippincott Williams and Wilkins.
- Kay, S., Fiszbein, A. & Opler, L. (1987). The positive and negative symptom scale (PANSS) for schizophrenia. *Schizophrenia Bulletin*, 13, 261-276.
- Kelly, M. & Gamble, C. (2005). Exploring the concept of recovery in schizophrenia. *Journal of Psychiatric and Mental Health Nursing*, 12, 245-251.
- Kilkku, N., Munnukka, T. & Lehtinen, K. (2003). From information to knowledge: The meaning of information-giving to patients who had experienced first-episode psychosis. *Journal of Psychiatric and Mental Health Nursing*, 10, 57-64.

- Killackey, E. & Yung, A. R. (2007). Effectiveness of early intervention in psychosis. *Current Opinion in Psychiatry*, 20, 121-125.
- Kuipers, E., Garety, P., Fowler, D., Dunn, G., Bebbington, P., Freeman, D., *et al.* (1997). London-East Anglia randomised controlled trial of cognitive-behavioural therapy for psychosis: effects of the treatment phase. *British Journal of Psychiatry*, 171, 319-327.
- Kuipers, E., Holloway, F. & Rabe-Hesketh, S. (2004). An RCT of early intervention in psychosis: the Croydon Outreach and Assertive Support Team (COAST). *Social Psychiatry and Psychiatric Epidemiology*, 39, 358-366.
- Kuhlmann, S., Piel, M. & Wolf, O. (2005). Impaired Memory Retrieval after Psychosocial Stress in Healthy Young Men. *Journal of Neuroscience*, 25, 2977-2982.
- Lambert, M., Conus, P., Lubman, D., Wade, D., Yuen, H. & Moritz, S. (2005). The impact of substance use disorders on clinical outcome in 643 patients with first-episode psychosis. *Acta Psychiatrica Scandinavica*, 112, 141-148.
- Larsen, J. (2007). Understanding a complex intervention: person centred ethnography in early psychosis. *Journal of Mental Health*, 16, 333-345.
- Larsen, T., McGlashan, T. & Johannessen, J. O. (2001). Shortened duration of untreated first episode of psychosis: Changes in patient characteristics at treatment. *American Journal of Psychiatry*, 158, 1917– 1919.
- Larsen, T., Melle, I., Auestad, B., Friis, S., Haahr, U., Johannessen, J., *et al.* (2006). Early detection of first episode psychosis: the effect on 1-year outcome. *Schizophrenia Bulletin*, 32, 758-764.
- Larsen, T., Melle, I., Friis, S., Joa, I., Johannessen, J., Opjordsmoen, S., *et al.* (2007). One year effect of changing duration on untreated psychosis in a single catchment area. *British Journal of Psychiatry*, 191, 128-132.
- Lauber, C., Eichenberger, A., Luginbuhl, P., Keller, C. & Rossler, W. (2003). Determinants of burden in caregivers of patients with exacerbating schizophrenia. *European Psychiatry*, 18, 285-289.
- Leavey, G., King, M., Cole, E., Hoar, A. & Johnson-Sabine, E. (1997). First-onset psychotic illness: patients' and relatives' satisfaction with services. *British Journal of Psychiatry*, 170, 53–57.
- Leese M., Johnson S., Slade M., Parkman, S., Kelly, F., Phelan, M. & Thornicroft, G. (1998). User perspective on needs and satisfaction with mental health services. *British Journal of Psychiatry*, 173, 409 – 415.

- Lester, H., Birchwood, M., Bryan, S., England, E., Rogers, H. & Sirvastava, N. (2009). Development and implementation of early intervention services for young people with psychosis: case study. *British Journal of Psychiatry*, 194, 446-450.
- Lester, H., Khan, N., Jones, P., Marshall, M., Fowler, D., Amos, T., *et al.* (2012). Service users' views of moving on from early intervention services for psychosis: a longitudinal qualitative study in primary care. *British Journal of General Practice*, 62, 136-137.
- Lewis, S., Tarrier, N., Haddock, G., Bentall, R., Kinderman, P., Kingdon, D., *et al.* (2002). Randomised controlled trial of cognitive-behavioural therapy in early schizophrenia: acute-phase outcomes. *British Journal of Psychiatry*, 181, 91-97.
- Ley, P., Bradshae, P. & Eaves, D. (1973). A method for increasing patient's recall of information presented by doctors. *Psychological Medicine*, 3, 217-220.
- Lieberman, J., Stroup, T., Joseph, M., Stroup, S., McEvoy, J., Swartz, M., *et al.* (2005). Effectiveness of antipsychotic drugs in patients with chronic schizophrenia. *The New England Journal of Medicine*, 353, 1209-1223.
- Linszen, D., Dingemans, M. & Lenior, M. (1994). Cannabis abuse and the course of recent-onset schizophrenic disorders. *Archives of General Psychiatry*, 51, 706-712.
- Linszen, D., Dingemans, P. & Lenoir, M. (2001). Early intervention and a five-year follow-up in young adults with a short duration of untreated psychosis: ethical implications. *Schizophrenia Research*, 51, 55-61.
- Linszen D., Dingemans P., Van Der Does J.W., Nugter, A., Scholte, P., Lenior, R., *et al.* (1996). Treatment, expressed emotion and relapse in recent onset schizophrenic disorders. *Psychological Medicine*, 26, 333-342.
- MacDonald, E., Sauer, K., Howie, L. & Albiston, D. (2005). What happens to social relationships in early psychosis? A phenomenological study of young people's experiences. *Journal of Mental Health*, 14, 129-143.
- Mackrell, L. & Lavender, T. (2004). Peer relationships in adolescents experiencing a first episode of psychosis. *Journal of Mental Health*, 13, 467-479.
- Magliano, L., Fiorillo, A., De Rosam, C., Malangone, C. & Maj, M. (2005a). Family burden in long term diseases: a comparative study in schizophrenia vs. physical disorders. *Social Science and Medicine*, 61, 313-322.
- Malla, A., Norman, R. & Voruganti, L. (1999). Improving outcome in schizophrenia: the case for early intervention. *Canadian Medical Association Journal*, 160, 843-846.
- Malla A, & Payne J. (2005). First-episode psychosis: psychopathology, quality of life, and functional outcome. *Schizophrenia Bulletin*, 31, 650-71.

- Mancini, M., Hardiman, E. & Lawson, H. (2005). Making sense of it all: consumer providers' theories about factors facilitating and impeding recovery from psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 29, 48–55.
- Marshall, M., Lockwood, A., Lewis, S. & Fiander, M. (2004). Essential elements of an early intervention service: the opinion of expert clinicians. *BioMedCentral Psychiatry*, 4, 17-19.
- Marshall, M., Lewis, S., Lockwood, A., Drake, R., Jones, P. & Croudace, T (2005). Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review. *Archives of General Psychiatry*, 62(9), 975-983.
- Marshall, M. & Rathbone, J. (2011). *Early intervention for psychosis*. Cochrane Database of Systematic Reviews (2011), Issue 6.
- Mays, N. & Pope, C. (2000). Qualitative research in health care: assessing quality in qualitative research. *British Medical Journal*, 320, 50-52.
- McCann, T., Lubman, D. & Clark, E. (2011). First time primary caregivers experiences of accessing first episode psychosis services. *Early Intervention in Psychiatry*, 5, 156-162.
- McGlashan, T. (1988). A selective review of recent North American long-term follow-up studies of schizophrenia. *Schizophrenia Bulletin*, 14, 515-542.
- McGlashan, T.H., Zipursky, R.B., Perkins, D., Addington, J., Miller, T., Woods, S.W., *et al.* (2006). Randomized, double-blind trial of olanzapine versus placebo in patients prodromally symptomatic for psychosis. *American Journal of Psychiatry*, 163, 790–799.
- McGorry, P. D., Edwards, J. & Mihalopoulos, C. (1996) *EPPIC*: An evolving system of early detection and optimal management. *Schizophrenia Bulletin*, 22, 305– 326.
- McGorry, P. (1997). *Very low dose neuroleptic treatment of first episode psychosis -is it feasible in routine clinical care?* Poster Presentation. 6th International congress of Schizophrenia Research, Colorado Springs.
- McGorry, P. (2000). The nature of schizophrenia: signposts to prevention. *Australian and New Zealand Journal of Psychiatry*, 34, 14-21.
- McGorry, P. & Edwards, J. (1997). *Early psychosis training pack*. Macclesfield, Cheshire: Gardiner-Caldwell Communications.
- McGorry, P. D., Edwards, J. & Mihalopoulos, C. (1996). EPPIC: An evolving system of early detection and EPPIC: An evolving system of early detection and optimal management. *Schizophrenia Bulletin*, 22, 305-326.

- McGorry, P., Hickie, I., Yung, C., Pantelis, H. & Jackson, N. (2006). Clinical staging of psychiatric disorders: a heuristic framework for choosing earlier, safer and more effective interventions. *Australian and New Zealand Journal of Psychiatry*, 40, 616-622.
- McGorry, P. & Jackson, H. (1999). *The Recognition and Management of Early Psychosis: A Preventative Approach*. Cambridge: Cambridge University Press
- McGorry, P. & Yung, A. (2003). Early intervention in psychosis: an overdue reform. *Australian and New Zealand Journal of Psychiatry*, 37, 393-398.
- McGorry, P., Yung, A. & Phillip, L. (2002). Randomised controlled trial of interventions designed to reduce the risk of progression to first episode psychosis in a clinical sample with sub-threshold symptoms. *Archives of General Psychiatry*, 59, 921-928.
- McKenzie, L. (2006). Service users and carers' experiences of a psychosis service. *Journal of Psychiatric and Mental Health Nursing*, 13, 636-640.
- Melle, I., Haahr, U. & Friis S. (2005). Reducing the duration of untreated first-episode psychosis: effects on baseline social functioning and quality of life. *Acta Psychiatrica Scandinavica*, 112, 469-473.
- Melle, L., Johannesen, J. & Friis, S. (2006). Early detection of the first episode of schizophrenia and suicidal behaviour. *American Journal of Psychiatry*, 163, 800-804.
- Melle, I., Larsen, T. & Haahr U. (2004). Reducing the duration of untreated first-episode psychosis. Effects on clinical presentation. *Archives of General Psychiatry*, 61, 143-150.
- Melle, I., Larsen, T., Haahr, U., Friis, S., Johannesen, J., Opjordsmoen, S., *et al.* (2008). Prevention of negative symptom pathologies in first episode schizophrenia: two year effects of reducing the duration of untreated psychosis. *Archives of General Psychiatry*, 65, 634-640.
- Mental Health Act (1983). Retrieved 29 December 2011 from http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_4002034
- Mohl, P., Martinez, D., Ticknor, C., Huang, M. & Cordell, L. (1991). Early drop-outs from psychotherapy. *The Journal of Nervous and Mental Disease*, 179, 478-481.
- Morrison, A., French, P., Parker, S., Roberts, M. & Stevens, H. (2007). Three-year follow up of a randomised controlled trial of cognitive therapy for the prevention of psychosis in people in ultrahigh risk. *Schizophrenia Bulletin*, 33, 682-687.
- Morton, A., Fairhurst, A. & Ryan, R. (2010). Promoting recovery: service user and staff perceptions of resilience provided by a new early intervention in psychosis service. *Early Intervention in Psychiatry*, 4, 89-92.

- Moyer, A., Schneider, J., Knapp-Oliver, S. & Sohl, S. (2010). Published versus unpublished dissertations in psycho-oncology intervention research. *Psycho-oncology*, 19, 313-317.
- Naik, V. & Bowden, S. (2008). Early intervention in psychosis: client and carer perspectives. *Nursing Times*, 104, 32-33.
- National Institute for Clinical Excellence (2002). *Schizophrenia: Core interventions in the treatment and management of schizophrenia in primary and secondary care*. London: National Institute for Clinical Excellence.
- National Institute for Clinical Excellence (2010). *Core interventions in the treatment and management of schizophrenia in primary and secondary care*. Retrieved 11th November 2011 from: <http://publications.nice.org.uk/schizophrenia-cg82>
- National Institute for Health and Clinical Excellence (2011). *Service users experiences in adult mental health: improving the experience of care for people using adult mental health service*. Retrieved 1st December 2011 from: <http://publications.nice.org.uk/service-user-experience-in-adult-mental-health-improving-the-experience-of-care-for-people-using-cg136/guidance>
- Noble, L., Douglas, B. & Newman, S. (1999). What do patients want and what do we know? A review of patients' requests of psychiatric services. *Acta Psychiatrica Scandinavica*, 100, 321-327.
- Nolan, M., Keady, J. & Grant, G. (1995). CAMI: a basis for assessment and support with family carers. *British Journal of Nursing*, 4, 822-826.
- Norman, R. & Malla, A. (2001). Duration of untreated psychosis: a critical examination of the concept and its importance. *Psychological Medicine*, 31, 381-400.
- Novak, M. & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist*, 29, 798-803.
- Nuechterlein, K. & Dawson, M. (1984) A heuristic vulnerability/stress model of schizophrenic episodes. *Schizophrenia Bulletin*, 10, 300-312.
- Nuechterlein, K., Dawson, M., Gitlin, M., Ventura, J., Goldstein, M., Snyder, K., *et al.* (1992). Developmental processes in schizophrenic disorders: longitudinal studies of vulnerability and stress. *Schizophrenia Bulletin*, 18, 387-425.
- Onyett, S. (2003). *Team Working in Mental Health*. Hampshire: Palgrave Macmillan.
- Ostman, M. & Kjellin, L. (2002). Stigma by association: Psychological factors in relatives of people with mental illness. *British Journal of Psychiatry*, 181, 494-498.

- O'Toole, M., Ohlsen, R. & Taylor, T. (2004). Treating first episode psychosis-the service users' perspective: a focus group evaluation. *Journal of Psychiatric and Mental Health Nursing*, 11, 319-326.
- Palmer, B., Pantratz, V. & Bostwick, J. (2005). The lifetime risk of suicide in schizophrenia: a re-examination. *Archives of General Psychiatry*, 62, 247-253.
- Parkman, S., Davies, S. & Leese, M. (1997). Ethnic differences in satisfaction with mental health services among representative people with psychosis in South London: PriSM study. *British Journal of Psychiatry*, 171, 260-264.
- Patterson, P., Birchwood, M. & Cochrane, R. (2005). Expressed emotion as an adaptation to loss: prospective study in first-episode psychosis. *British Journal of Psychiatry*, 187, 59-64.
- Paynter, S., Williams, S., Jackson, M., Baird, J. & Rudd, L. (2011). *1000+ Lives Programme: First Episode Psychosis-Intelligent Target*. Retrieved 1st December 2011 from <http://www.wales.nhs.uk/sites3/Documents/781/FEP%20How%20to%20Guide%20DRAFT.pdf>
- Pelosi, A. (2009). Is early intervention in the major psychiatric disorders justified? No. *British Medical Journal*, 337, a710.
- Pelosi, A. & Birchwood, M. (2003). Is early intervention for psychosis a waste of valuable resources? *British Journal of Psychiatry*, 182, 196-198.
- Penny, E., Newton, E. & Larkin, M. (2009). Whispering on the water: British Pakistani families' experiences of support from an early intervention service for first-episode psychosis. *Journal of Cross Cultural Psychology*, 40, 969-987.
- Perkins, R. (2006). First person: 'you need hope to cope'. In Roberts, G., Davenport, S., Holloway, F. & Tattan, T. (Eds.) *Enabling Recovery: The principles and practice of rehabilitation psychiatry* (pp.345-372). London: Gaskell.
- Perkins, D., Gu, H., Boteva, K. & Lieberman, J. (2005). Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: a critical review and meta-analysis. *American Journal of Psychiatry*, 162, 1785-1804.
- Petersen, L., Jeppesen, P., Thorup, A., Abel, M., Ohlenschlaeger, J., Christensen, T., *et al.* (2005). A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *British Medical Journal*, 331, 602-607.
- Pharoah, F., Mari, J., Rathbone, J. & Wong, W. (2010). *Family intervention for schizophrenia*. Cochrane Database of Systematic Reviews 2010, Issue 12.
- Phelan, J., Bromet, E. & Link, B. (1998). Psychiatric illness and family stigma. *Schizophrenia Bulletin*, 24(1), 115-126.

- Piat, M., Lesage, A., Boyer, R., Douril, H., Couture, A., Grenier, G., *et al.* (2008). Housing for persons with severe mental illness: consumers' and service providers' preferences. *Psychiatric Services*, 59, 56-72.
- Pilgrim, D. (2008a). Recovery and current mental health policy. *Chronic Illness*, 4, 295-304.
- Pilling, S., Bebbington, P. & Kuipers, E. (2002). Psychological treatments in schizophrenia: meta analysis of family intervention and cognitive behaviour therapy. *Psychological Medicine*, 32, 763-782.
- Pinfold, V., Farmer, P., Rapaport, J., Bellringer, S., Huxley, P., Murray, M., *et al.* (2004). *Positive and inclusive? Effective ways for professionals to involve carers in information sharing*. Report for the National Co-ordinating centre for NHS Service Delivery and Organisation R & D.
- Pinfold, V. & Smith, J. (2007). Audit of early intervention in psychosis service development in England in 2005. *The Psychiatrist*, 31, 7-10.
- Pinquart, M. & Sorensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *Journal of Gerontology: Psychological Sciences and Social Sciences*, 62, 126-137.
- Power, P., Bell, R. & Mills, R. (2003). Suicide prevention in first episode psychosis: the development of a randomised controlled trial of cognitive therapy for acutely suicidal patients with early psychosis. *Australian and New Zealand Journal of Psychiatry*, 37(4), 414-420.
- Priebe, S., Huxley, P. & Knight, S. (1999). Application and results of the Manchester short assessment of quality of life (MANSA). *International Journal of Social Psychiatry*, 45, 7-12.
- Quirk, A. & Lelliott, P. (2001). What is life like on acute psychiatric wards? *Current Opinion in Psychiatry*, 17, 297-301.
- Ralph, R. (2000). Recovery. *Psychiatric Rehabilitation Skills*, 4, 201-213.
- Ramon, S., Healy, B. & Renouf, N. (2007). Recovery from mental illness as an emergent concept and practice in Australia and the UK. *International Journal of Social Psychiatry*, 53(2), 108-122.
- Raune, D., Kuipers, E. & Bebbington, P. (2004). Expressed emotion at first episode psychosis: investigating a carer appraisal model. *British Journal of Psychiatry*, 184, 321-326.
- Read, J. (2005). The bio-bio-bio model of madness. *The Psychologist*, 10, 596-597.

- Reicher, S. (2000). Against methodolatory; some comments on Elliott, Fischer and Rennie. *British Journal of Clinical Psychology*, 39, 1-6.
- Reinhard, C. (1994). Living with mental illness: effects of professional support and personal control on caregiver burden. *Research in Nursing & Health*, 17, 79-88.
- Repper, J. & Perkins, R. (2003). *Social Inclusion and Recovery*. London: Balliere Tindall.
- Rethink (2003). *Getting your facts straight*. Retrieved 11th November 2011 from http://www.rethink.org/how_we_can_help/our_campaigns/local_campaigning/so_you_want_to_change_the_world/getting_your_facts_s.html
- Rethink (2009). *100 ways to support recovery: a guide for mental health professionals*. Retrieved 20th January 2012 from http://www.rethink.org/mental_health_shop/products/rethink_publications/100_ways_to_support.html?shortcut=100ways
- Ridgeway, P. (2005). Developing Recovery Enhancing Environment Measure (DREEM). In T. Campbell., J. Chamberlin., J. Carpenter & H. Leff (Eds.) *Measuring the promise: a compendium of recovery measures*. Cambridge: MA.
- Riley, G., Gregory, N., Bellinger, J., Davies, N., Mabbott, G. & Sabourin, R. (2011). Carers' education groups for relatives with a first episode of psychosis: an evaluation of an eight-week education group. *Early Intervention in Psychiatry*, 5, 57-63.
- Ritchie, J., Dick, D. & Lingham, R. (1994). *Report of the Committee of Inquiry into the Care of Christopher Clunis*. London: MIND/COHSE.
- Roberts, G. & Wolfson, P. (2004). The rediscovery of recovery: open to all. *Advances in Psychiatric Treatment*, 10, 37-48.
- Roberts, L., Warner, T. & Anderson, C. (2004). Schizophrenia research participants responses to protocol safeguards: recruitment, consent and debriefing. *Schizophrenia Research*, 67, 283-291.
- Robinson, D., Woerner, M., Alver, J., Bilder, R., Goldman, R., Geisler, S., *et al.* (1999). Predictors of relapse following response from a first episode of schizophrenia or schizoaffective disorder. *Archives of General Psychiatry*, 56, 241-247.
- Robinson, D., Woerner, M., Delman, H. & Kane, J. (2005). Pharmacological treatments for first-episode schizophrenia. *Schizophrenia Bulletin*, 31, 705-722.
- Rogers, A. & Pilgrim, D. (2001). *Mental Health Policy in Britain* (2nd Ed). Basingstoke: Palgrave.

- Roick, C., Heider, D. & Bebbington, P. (2007) Burden on caregivers of people with schizophrenia: comparison between Germany and Britain. *British Journal of Psychiatry*, 190, 333-338.
- Rose, D. (2001). *Users' Voices*. London: The Sainsbury Centre for Mental Health.
- Rosenfarb, I., Bellack, A. & Aziz, N. (2006). A sociocultural stress, appraisal, and coping model of subjective burden and family attitudes toward patients with schizophrenia. *Journal of Abnormal Psychology*, 115, 157-165.
- Ross, M., Norman, B., Shon, W. & Marshall, M. (2005). Duration of untreated psychosis and relationship to clinical outcome. *British Journal of Psychiatry*, 187, 19-23.
- Ruggeri, M. & Dall'Agnola, R. (1993). Development and use of the Verona Expectations for Care Scale (VECS) and the Verona Service Satisfaction Scale (VSSS) for measuring expectations and satisfaction with community-based psychiatric service in patients, relatives and professionals. *Psychological Medicine*, 23, 511-523.
- Ruhrmann, S., Schultze-Lutter, F., Maier, W. & Klosterkötter J. (2005). Pharmacological intervention in the initial prodromal phase of psychosis. *European Psychiatry*, 20, 1-6
- Russell, A.T., Bott, L. & Sammons, C. (1989). The phenomenology of schizophrenia occurring in childhood. *Journal of the American Academy of Child and Adolescent Psychiatry*, 28, 399-407.
- Ryan, A. K. (1993). Mothers of adult children with schizophrenia: An ethnographic study. *Schizophrenia Research*, 11, 21-31.
- Sainsbury Centre for Mental Health (1998). *Keys to Engagement: Review of care for people with severe illness who are hard to engage with services*. London: The Sainsbury Centre for Mental Health.
- Sainsbury Centre for Mental Health (2003). *A Window of Opportunity: A Practical Guide for Developing Early Intervention in Psychosis Services*. London: The Sainsbury Centre for Mental Health.
- Sanbrook, M. & Harris, A. (2003). Origins of early intervention in first-episode psychosis. *Australasian Psychiatry*, 11(2), 215-219.
- Sanbrook, M., Harris, A., Parada, R. & Young, P. (2003). The effectiveness of an early intervention team in the treatment of first-episode psychosis. *Australian e-Journal for the Advancement of Mental Health*. Retrieved 14 February 2012 from <http://www.auseinet.com/journal/vol2iss1/Sanbrook.pdf>
- Sandelowski, M. (1995b). Sample size in qualitative research. *Research in Nursing and Health*, 18, 179-183.

- Schrank, B. & Slade, M. (2007). Recovery in Psychiatry. *Psychiatric Bulletin*, 31, 321-325.
- Schulze, B. & Angermeyer, M. C. (2003). Subjective experiences of stigma: a focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science and Medicine*, 56, 299–312.
- Schulze, R. & Sherwood, P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108, 23-27.
- Sensky, T., Turkington, D. & Kingdon, D. (2000). A randomised controlled trial of cognitive-behavioural therapy for persistent symptoms in schizophrenia resistant to medication. *Archives of General Psychiatry*, 57, 165-172.
- Shah, A., Wadoo, O. & Latoo, J. (2010). Psychological distress in carers of people with mental disorder (Electronic version). *British Journal of Medical Practitioners*, 3, 327-334.
- Shepherd, G., Boardman, J. & Slade, M. (2008) *Making Recovery a Reality*. London: Sainsbury Centre for Mental Health.
- Shepherd, G., Murray, A. & Muijen, M. (1994). *Relative Values: The Differing Views of Users, Family Carers and Professionals on Service for People with Schizophrenia in the Community*. London: The Sainsbury Centre for Mental Health.
- Shield, H., Fairbrother, G. & Obmann, H. (2005). Sexual health knowledge and risk behaviour in young people with first episode psychosis. *International Journal of Mental Health Nursing*, 14, 149–154.
- Shore, L. (2006). Inside caring in mental health. In C.Gamble & G. Brenna (Eds.) *Working with Serious Mental Illness: A Manual for Clinical Practice* (2nd edn., pp.11-22). London: Elsevier.
- Sin, J., Moone, N. & Wellman, N. (2007). Developing services for carers of young adults with early-onset psychosis – implementing evidence-based practice on psycho-educational family intervention. *Journal of Psychiatric and Mental Health Nursing*, 14, 282-290.
- Singh, S.P. (2010) Early intervention in psychosis. *British Journal of Psychiatry*, 176, 210-216.
- Singh, S. & Grange, T. (2006). Measuring pathways to care in first episode psychosis-a systematic review. *Schizophrenia Research*, 81, 75-82.
- Singleton, N., Bumpstead, R. & O'Brien, M. (2001). *Psychiatric Morbidity among Adults Living in Private Households: National Statistics*. London: Stationery Office.

- Smyth, J., Webb, M. & Oikawa, M. (2000). *Self report of cancer-related behaviours*. Unpublished manuscript.
- Spandler, H., Secker J. & Kent L. (2007). Catching life: the contribution of arts initiatives to recovery approaches in mental health. *Journal of Psychiatric and Mental Health Nursing* 14, 791–199.
- Stanbridge, R., Burbach, F., Lucas, A. & Carter, K. (2003). A study of families' satisfaction with a family interventions in psychosis service in Somerset. *Journal of Family Therapy*, 25, 181-204.
- Staniszewska, S. & Ahmed, L. (1999). The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? *Journal of Advanced Nursing*, 29, 364-372.
- Stanley, K., Lewis, O. & Abraham, F. (1986). *Positive and negative syndrome scale (PANSS) rating manual*. New York: MSCRU.
- Starks, H. & Trinidad, S. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*, 17, 1372-1380.
- Stein, C. & Wemmerus, V. (2001). Searching for a normal life: personal accounts of adults with schizophrenia, their parents and well-siblings. *American Journal of Community Psychology*, 29, 725-746.
- Stern, P. (1980). Grounded theory methodology: its uses and processes. *Image*, 12, 20-23.
- Strauss, A., and Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. CA: Sage.
- Szmuckler, G., Burgess, P. & Hermann, H. (1996). Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. *Society for Psychiatry and Psychiatric Epidemiology*, 31, 137-148.
- Szmukler, G., Kuipers, E. & Joyce, J. (2003). An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 38, 411-418.
- Tait, L., Birchwood, M. & Trower, P. (2002). A new scale (SES) to measure engagement with community mental health services. *Journal of Mental Health*, 11, 191-198.
- Tanskanen, S., Morant, N., Hinton, M., Lloyd-Evans, B., Crosby, M. & Killaspy, H. (2011). Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study. *BMC Psychiatry*, 11, 157-164.

- Tarrier, N. & Bobes, J. (2000). The importance of psychosocial interventions and patients involvement in the treatment of schizophrenia. *International Journal of Psychiatry in Clinical Practice*, 4, 35-51.
- Tarrier, N., Lewis, S., Haddock, G., Bentall, R., Drake, R., Kinderman, P., *et al.* (2004). Cognitive behavioural therapy in first episode and early schizophrenia. *British Journal of Psychiatry*, 184, 231-239.
- Theuma, M., Read, J., Moskowitz, A. & Stewart, A. (2007). Evaluation of a New Zealand early intervention service for psychosis. *New Zealand Journal of Psychology*, 36, 136-145.
- Thorup, A., Peteresen, L., Jeppesen, P., Ohlenschlager, J., Chistiansen, T., Krarup, G., *et al.* (2005). Integrated treatment ameliorates negative symptoms in 1st episode psychosis – results from the Danish OPUS trial. *Schizophrenia Research*, 79, 95-105.
- Tsuang, M., Stone, W. & Farone, S. (2000). Towards reformulating the diagnosis of schizophrenia. *American Journal of Psychiatry*, 157, 1041-1050.
- Tuck, I., du Mont, P. & Evans, G. (1997). The experience of caring for an adult child with schizophrenia. *Archives of Psychiatric Nursing*, 70, 268-273
- Tyson, P., Ayton, A., Al Agib, A., Bowie, P., Worrall-Davies, A. & Mortimer, A. (2001). A comparison of the service satisfaction and intervention needs of patients with schizophrenia and their relatives. *International Journal of Psychiatry in Clinical Practice*, 5, 263-271.
- Veltman, A., Cameron, J. & Stewart, D. (2002). The experience of providing care to relatives with chronic mental illness. *Journal of Nervous Disease and Mental Disease*, 190, 108-114.
- Verdoux, H. (2001). Have the times come for early intervention in psychosis? *Acta Psychiatrica Scandinavica*, 103, 321-322.
- Verdoux, H., Lengronne, J., Liraud, F., Gonzales, B., Assens, F., Abalan, F., *et al.* (2000). Medication adherence in psychosis : predictors and impact on outcome. A 2-year follow-up of first-admitted subjects. *Acta Psychiatrica Scandinavica* 102, 203–210.
- Vasquez, M., Bingham, R. & Barnett, J. (2008). Psychotherapy termination: clinical and ethical responsibilities. *Journal of Clinical Psychology*, 64, 653-665.
- Wade, D., Harrigan, S. & Edwards, J. (2006) Course of substance misuse and daily tobacco use in first-episode psychosis. *Schizophrenia Research*, 81, 145–150.
- Warner, R. (2005). Problems with early and very early intervention in psychosis. *The British Journal of Psychiatry*, 187, 104-107.

- Welsh Assembly Government (2005). *Designed for Life: Creating world class health and social care for Wales in the 21st century*. Cardiff: Welsh Assembly Government.
- Williams, B. (1994) Patient satisfaction: a valid concept. *Social Science and Medicine*, 38, 509-516.
- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham: Open University Press.
- Wing, J., Beevor, A., Cutis, R., Park, S., Hadden, S. & Burns, A. (1998). Health of the Nation Scale (HoNoS): Research and Development. *British Journal of Psychiatry*, 172, 11-18.
- Woltraus, J., Dingemans, P. & Schene A. (2002). Caregiver burden in recent-onset schizophrenia and spectrum disorders: the influence of symptoms and personality traits. *Journal of Nervous and Mental Disease*, 190, 241–247.
- World Health Organisation (1992). *International Statistical Classification of Diseases and Related Health Problems* 10th Ed. Geneva: World Health Organisation.
- World Health Organization (2002). *Mental Health Global Action Programme*. Retrieved 12 December 2011 from http://www.who.int/whr/2001/en/whr01_en.pdf
- Wyatt, R. (1991). Neuroleptics and the natural course of schizophrenia. *Schizophrenia Bulletin*, 17, 325-351.
- Yung, A. (2012). Early intervention in psychosis: evidence, evidence gaps, criticism and confusion. *Australian and New Zealand Journal of Psychiatry*, 46, 7-9.
- Yung, R., Phillips, L., Yuen, H. & McGorry, P. (2004). Risk factors for psychosis in an ultra-high risk group: psychopathology and clinical features. *Schizophrenia Research*, 67, 131-142.

APPENDICES

APPENDIX 1

Key Terms used for Database Search Strategy

Key Terms used for Database Search Strategy

Early Intervention

Psychosis Service

Early Psychosis Treatment Teams

EPPIC Early detection service (Australia)

Early Assessment and Support Alliance (USA)

First Episode Psychosis Programme

Early Assessment and Support Team (EAST)

Early Detection and Intervention Services (EDIS) (Canada)

Early Assessment Services for Young People with Psychosis (EASY) (Hong Kong)

Early Psychosis Intervention Programme (Singapore)

Early Treatment and Identification of Psychosis (TIPS) (Norway)

Early Psychosis Prevention and Intervention Service (EPPIS) (Canada)

APPENDIX 2

Journals included in the manual search strategy

Journals included in the manual search strategy

Acta Psychiatrica Scandinavica

Early Intervention in Psychiatry

Psychiatric Bulletin

Schizophrenia Bulletin

APPENDIX 3

Data Extraction Tool

Data Extraction Tool

Reference	Design and Objective	Number of participants	Age/gender	Diagnosis or other defining characteristics of the population	Measures employed	Key findings	Limitations (internal and external validity)

APPENDIX 4

Example of a Coded Transcript

Example of a Coded Transcript

I generally first start by asking how you've become involved with the early intervention team?

prev. since involvement
suddenness / out the blue - very picked up? shocking.
I had two breakdowns, but I wasn't aware of it. They happened sudden like. It was my family and all that, that were aware of it, and they made me go and get help you know, for the things that I was doing like. Strange and odd and all that like. But with the early intervention team, they stopped me wanting to kill myself, I was really bad at one point with that one, I wouldn't stop trying to kill myself like. But with talking to the early intervention team, like X, and with the help of them coming to see me at home, instead of having to go in the nuthouse (psychiatric unit) and talking to me and all that, it slowly brought me out of it you know.

Centrality of family in all that tx.

- extreme distress

stigmatising language for m.h.

Context - home important over hospital tx.

Difficult making sense of the exp? - Exhaustion?

Having somebody there?

Could you tell me a bit more about that?

Well, it was just X talking to me at the start. At the time it didn't matter how many times my family told me, I wasn't listening to them. But with the early intervention team, it's their perseverance. They don't let up and they get to the bottom of something. So after a few months X started getting me out of the house, once a week and all that. And then he introduced me to XX (horticultural programme) and a woodworking shop down there and all that, carpentry and everything. It has done me good.

Perseverance Again!

Shady persistence of team BUT could this be invasive? what about if you don't want them??

impaired? objective conclusions?

Meaningful occupation.

What do you think was different about the early intervention team that made you able to talk to them?

Positive staff characteristics that promote engagement, therapeutic relationship?

They seemed really warm and friendly, really warm and kind you know? And some of the things they talk about, it really triggers you off like you know, to think happy or be happy.

What kind of things? Have you got any examples?

Promoting hope / optimism
or hope - of CBT??
skills + future of staff

Well, anything they come across they've got a way of making you look at it in a different way so things don't look so dark and it makes you feel better, and just talking crap basically, getting you laughing and some of the things that they're into, you know?

Treating you as a normal person.

So just talking about normal things?

Yeah normal things, like I say, with X he treats you as an individual, not just another number. That's the way you feel with X. He's always on about when I used to go fishing with the boys and surfing.

And that sounds like it's a good thing for you?

Hopefulness - looking to the future.
↓
Inversion = hopelessness (from 611)?

Yeah. The only way I can explain it is just like a new lease of life, or I'm starting to gain a new lease of life again. I won't go into all my problems or anything, but just things that have happened have really affected me, but I didn't realise how much they were affecting me and how much they were making me bad. I thought there was nothing wrong with me. The more I was becoming ill, the more I thought everyone was trying to make me bad.

↓
Paranoia - act as a barrier to engagement in team?

So how did they get through?

facing?

Trustworthiness & staff imp

Well they start off slow and you start to trust them. They get you talking, keep you talking, and that's I think mainly the key, is being able to talk to you and getting you to loosen up. They've never rushed me, I'll give them that. They've never, right you've got to start thinking, you've got to do this, none of that. None of, you've got to do this or you've got to do that, none of that kind of pressure. It was always, maybe try doing this and try doing that. It's like with X isn't it? You've got to get out. Never mind sitting in all day. 'Your dog's crossing his legs,' I said, 'I'll let him out X.' He comes back like, 'No it's

Taking things at the individual person.

Collaborative working?

not fair, the dog needs walking.' And he kept trying to get me to walk the dog. He's right, you know, get out a little bit more, a little bit more, a little bit further, different direction, sometimes not at night, sometimes in the day, sometimes in the morning. Just slowly a little bit, and I'm realising. And it's really refreshing. It's like washing your face. He put me on the right path and helped me stay on it.

gradual
movement

Guidance - Again!

what is this?
awakening?
starting again?
shocking?
+ve characteristic of staff

Can you say a little bit more about that?

You feel energised then when they've gone. Because they've got so much energy, the things you talk about, they don't give you time to think. Before you answer that one there's something else, and the next thing you know you're laughing about it, and you haven't laughed for a while. Brilliant, having him here for an hour.

What were your expectations of the service when they turned up, if you had any?

limited prior knowledge
of the service - why?
info given? written info?

barriers
to
engagement

I didn't have any expectations. I didn't know what anything was about, I didn't even want help. I was in denial that I was ill or anything. People who were close to me, who I do listen to anyway, but I wasn't. My family were telling me that I wasn't well. No, there's nothing wrong with me. Totally wouldn't see what people were seeing, or I couldn't see it. I couldn't adhere to the fact that people were telling me that I was unwell.

APPENDIX 5

Examples of Memoing

Examples of Memoing

October 27th 2011

First carer interview. Much harder than I imagined and I felt enormous sadness when listening to the hardship that the family had experienced throughout his wife's illness and the huge impact the breakdown had had on the family (e.g. the relationship between him and his wife, the impact on their young children, the financial difficulties). He also clearly articulated that the illness had been sudden and spoke about the fear he had felt when she had been admitted to a psychiatric unit (people were 'mad and dangerous'). Additionally, I was struck by the manner in which he described the relationship with the key EIS staff member ('worth her weight in gold' - in that he couldn't praise her highly enough. ?Positive bias? In other thoughts I need to get this transcribed as I have another on the 29th!

October 29th 2011

First client interview. Again high praise for the early intervention- I got the sense of almost the EIS staff member being talked about in an *angelic* way and at the same time a scent of potential dependency? Although, I guess this may be understandable as the service by its nature works intensively with individuals over a long period (3 years). However, interestingly she spoke at length about her traumatic (and horrific) experiences of being an inpatient – being given several different types of neuroleptic medication, never being told that recovery was possible and having poor relationships with the inpatient staff. Part of me is feeling slightly concerned as these negative experiences of past mental health services have arisen in both of my first interviews and I worry that I am being sidetracked from the issue of my study? However, at the same time I am trying to hold that this is an important piece of the puzzle/part of the overall experience.

1st November 2011

Second carer interview. I am again struck by my overwhelming feelings of sadness and desperation after this interview. I just felt like crying - which is really quite unusual as I am generally able to sit with such emotions. Perhaps there is something difficult about not being able to do anything (immediately as a researcher?) in opposition to my typical role as a trainee psychologist. Regardless, my impression was that the central theme here was that

something more needs to be done. It was clear that the service was not meeting some of her needs (?) as she spoke of the need for individual support (which had not been provided) as there were parts of the journey that were ‘more difficult for the carer’. However, she also spoke about the process of recovery and the importance of being provided with information by a specialist team (who knew what they were talking about!) and by the same member of staff ‘continuity is important when you are dealing with something like this’ - identifying that she felt she had resonated with the ‘stages’ of recovery they had talked about.

9th November 2011

Third carer interview. My first thoughts are how am I going to make sense of this and how can I transcribe it! She spoke in great detail about faith and family in recovery and also similarly to the 1st client interview appeared genuinely traumatised at the treatment she and her daughter had received whilst in a psychiatric inpatient unit. A small part of me is a bit concerned that I let the interview run away (need to improve on technique maybe?) and another part thinks that that’s how you get to the information which is important. Frustratingly, at the end after I had turned the tape off she began talking about how if she hadn’t have had the EIS she would have ‘cracked up’. I was able to write some of the narrative verbatim but I perhaps need to be mindful of the potential for this in further interviews.

December 5th 2011

Second client interview. Again similar to the previous interviews the participant talked a lot about the events leading up to their involvement with the service (past negative experiences of mental health services, suddenness of illness, emotional impact of the breakdown). The theme of the importance of information from a specialist service and the value of working with the same person also came up during the interview. However, interestingly, he spoke about feeling that the service should be more tailored to the individual – this is a new theme, and valuable given the importance of person centred care in early intervention service delivery.

APPENDIX 6

Local Health Board Research and Development Letters of Approval



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd
Aneurin Bevan
Health Board

**Research & Development
Research Scrutiny Committee
Tel: 01633 656353
Email: Michael.Morgan@wales.nhs.uk**

Jessica Woolley
16 Garden Flat
Redland Oak
Bristol
BS6 6SB

Ref: RSC.11.11
7th March 2011

Dear Jessica,

**An exploration of clients and carers experiences of an early intervention for psychosis service
Reg: RD/942/11**

The Committee agreed that the project was very comprehensive, well written and had no real faults. The Committee agreed that this project was an exemplary example of how research projects should be written.

Two minor points that were noted as needing amending:

- Section 7A the abbreviation 'EIPS' needs to be written in full
- A definition of the term 'Dyad' should be included.

It was agreed the project be approved.

I wish you every success with this project.

Please note that no substantial changes or amendments can be made to the protocol without notifying the Trust Research & Development Office.

Kind regards

AP Professor Sue Bale
**Chairman
Research Scrutiny Committee**

Y Friars
Ffordd Friars
Casnewydd
De Cymru
NP20 4EZ
Ffôn: 01633 234234

The Friars
Friars Road
Newport
South Wales
NP20 4EZ
Tel: 01633 234234

Bwrdd Iechyd Aneurin Bevan yw enw gweithredol Bwrdd Iechyd Lleol Aneurin Bevan
Aneurin Bevan Health Board is the operational name of Aneurin Bevan Local Health Board



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Ysbyty Athrofaol Cymru University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

21 July 2011

Miss. Jessica Woolley
Trainee Clinical Psychologist
Cardiff and Vale University Health Board
77 Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

Dear Miss. Woolley

Project ID : 11/MEH/5066 : An Exploration of Clients' and Carers' Experiences Of An Early Intervention for Psychosis Services (EIPS)

Further to recent correspondence regarding the above project, I am now happy to confirm receipt of:

- Evidence of favourable opinion from the relevant NHS Research Ethics Committee
- Revised documentation as required by the REC in order to obtain favourable opinion

The following amended documentation is approved for use with this study:

Documents	Version	Date
Protocol	1.7	18 June 2011
Patient Information Sheet: Carer	1.6	18 June 2011
Patient Information Sheet: Client	1.6	18 June 2011
Semi Structured Interview Schedule: Client	1.5	02 May 2011
Patient Consent Form	1.3	18 June 2011

Please accept this letter as confirmation of sponsorship by Cardiff and Vale UHB and permission for the project to begin.

May I take this opportunity to wish you success with the project, and to remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D Office if any external or additional funding is awarded for this project in the future
- Inform the R&D Office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D Office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the Data Protection Act 1998
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the Human Tissue Act, 2004 (for further information please contact Sharon Orton, HTA Coordinator OrtonS@cf.ac.uk).

If you require any further information or assistance, please do not hesitate to contact staff in the R&D Office.

Yours sincerely,



Professor Jonathan I Bisson
Cardiff and Vale University Local Health Board R&D Director

CC R&D Lead Prof Nick Craddock

APPENDIX 7

Local Research Ethics Committee Letter of Approval



South East Wales Research Ethics Committee
Sixth Floor, Churchill House
17 Churchill Way
Cardiff CF10 2TW

Telephone : 029 2037 6823

27 June 2011

Miss Jessica Laure Woolley
Trainee Clinical Psychologist
Cardiff and Vale University Health Board
Archway House, 77 Ty Glas Avenue
Llanishen, Cardiff
CF 14 5DX

Dear Miss Woolley

Study title: An Exploration of Clients' and Carers' Experiences of an
Early Intervention for Psychosis Service (EIPS)
REC reference: 11/WA/0145

Thank you for your letter of 24 June 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Dr K Craig.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

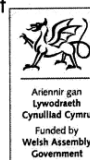
Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.



Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer
Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science
Collaboration is hosted by Powys Teaching Health Board



Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV	J Wooley	12 May 2011
Other: Letter from Aneurin Bevan HB		07 March 2011
Other: Letter from Aneurin Bevan RRRRC		08 March 2011
Other: Letter from C&V Research Review Service		18 February 2011
Participant Consent Form	1.3	18 June 2011
Participant Information Sheet: Carer	1.6	18 June 2011
Participant Information Sheet: Client	1.6	18 June 2011
Protocol	1.6	02 May 2011
Questionnaire: Semi Structured Interview Schedule - Client	1.5	02 May 2011
Questionnaire: Semi Structured Interview Schedule - Carer	1.4	27 December 2010
REC application	3.1	12 May 2011
Response to Request for Further Information	J Woolley	24 June 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/WA/0145

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely


Dr K J Craig
Chair

Email: jagit.sidhu@bsc.wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: R&D Office, Cardiff & Vale University Health Board

APPENDIX 8

Participants Information Sheet: Client Version

Participants Information Sheet: Client Version



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Participant Information Sheet

Version 1.6 (18.06.2011)

Client

Study Title: An Exploration of Clients' and Carers' Experiences of an Early Intervention for Psychosis Service (EIPS)

Researcher: Jessica Woolley

*I would like to invite you to take part in a research study. Before you decide, I would like you to understand why the research is being done and what it would involve for you. **One of the Early Intervention team members will go through the information sheet with you and answer any questions you have.** Talk to others about the study if you wish. (Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study). Please ask a member of the Early Intervention Team or contact me (Jessica Woolley) on the number provided overleaf if there is anything that is not clear.*

PART 1

Who is organising and funding the study?

I (Jessica Woolley, Trainee Clinical Psychologist employed by Cardiff and Vale University Local Health Board) am organising the research as part of my Doctorate in Clinical Psychology. There are no external bodies funding this study.

What is the purpose of the study?

The research aims to develop a better understanding of service users' and carers' experiences of the Early Intervention Service. It is hoped that this information will help the Early Intervention Service to develop in helpful ways.

Why have I been invited?

You are receiving this invitation because you are currently in contact with the Early Intervention for Psychosis Service.

It is hoped that at least 16 people (8 clients and 8 carers) will take part.

Do I have to take part?

It is up to you whether or not you decide to join the study. If you wish to take part I will ask you to sign a consent form to show that you have agreed to take part, and you will be given a signed copy of this to keep. You are free to withdraw at any time, without giving a reason. Whether or not you take part will not affect the services you receive from the Early Intervention Service.

What will happen to me if I take part?

If you agree to participate in this study, I will meet with you in the local hospital out-patient unit, or if you prefer, at your home address, at a time convenient to you, to conduct an interview. This should take about an hour. During this interview, I will ask you to talk about your experiences and views of the Early Intervention Service and staff. There are no right or wrong answers. You will have full control over what is said, and can take a break and/or stop the interview whenever you need. The interview will be audio taped, with your permission, and at a later stage, it will be transcribed. Any information that identifies you will be removed during transcription, and the audiotape will be destroyed immediately following transcription.

If you, and the person who is nominated as your carer, agree to take part in the study you will be offered separate interviews on different days. The information elicited in each interview will not be disclosed in the other interview.

What are the possible disadvantages or risks of taking part?

During the interview, it is possible that recollecting or talking about your experiences may be upsetting. If you feel distressed, and want the interview to stop, we can terminate the interview at any time. A member of the Early Intervention Team will be contactable (by telephone) after the interview should you feel the need for additional support.

What are the possible benefits of taking part?

There are no direct benefits to you personally in taking part but the information you provide may assist in developing the service and enabling individuals and families using the Early Intervention for Psychosis Service to be better supported in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this leaflet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2 of this leaflet.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time. If you let me know, I will stop the interview or, if you decide to withdraw after the interview, I will remove the information that you have provided from the study.

What if there is a problem?

If you have a concern about any aspect of the study, please contact me (Jessica Woolley), xx (Clinical Lead for the Early Intervention for Psychosis Service in x Local Health Board) or Professor Neil Frude (Senior Academic Research Tutor at South Wales Doctoral Training Programme for Clinical Psychology) via the contact details below. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from: <http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx>. Telephone: 0845 120 3782

Will my taking part in this study be kept confidential?

Yes. All the information you give will remain anonymous and strictly confidential. All identifying information, such as your name, will be removed so you cannot be identified. Your signed consent form will be stored in a locked cabinet in Archway House (base for the Doctoral Programme in Clinical Psychology). However, if you disclose information that means that either you or another person are at risk this may mean I have to pass on the information to the relevant services in order for them to take the appropriate action. If such an eventuality were to occur this would be discussed with you.

What will happen to the results of the research study?

When the interviews have been conducted, I (Jessica Woolley) will analyse the data and report the findings. These will be submitted to Cardiff University as a doctoral thesis and may be published in a journal. If you would like a copy of the final paper or a summary of the findings, I would be happy to provide this. Audiotapes will be destroyed immediately following transcription, and the transcripts will be destroyed five years after the completion of the study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect the safety, rights, well being and dignity of those who take part. This study has been reviewed and given a favourable opinion by South East Wales Research Ethics Committee.

Further information and contact details

If you would like to take part in the study, or if you have any questions/require further information, please contact me (Jessica Woolley) at the South Wales Doctoral Programme in Clinical Psychology, Archway House, 77 Ty Glas Avenue, Llanishen, Cardiff, CF14 5DX. Telephone: 02920 206464.

If you would like independent advice about your rights as a research participant you can either contact the NHS Patient Advice and Liaison Service (PALS) on 0117 928 3571 (www.pals.nhs.uk) or the Community Health Council (Wales) on 02920 235 55(www.communityhealthcouncils.org.uk).

If you have a concern about any aspect of the study, please contact;

Professor Neil Frude (Senior Academic Research Tutor at South Wales Doctoral Programme for Clinical Psychology): Archway House, 77 Ty Glas Avenue, Llanishen, Cardiff, CF14 5DX. Telephone: 02920 206464.

xx (Clinical Lead for Early Intervention for Psychosis Services x Local Health Board)

Many thanks for giving this invitation your time and consideration



1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff CF14 5DX

Ty Archway, 77 Ty Glas Avenue, Llanishen, Caerdydd CF14 5DX

Tel/Ffon 029 2020 6464 Fax/Ffacs 029 2019 0106

Email/Ebost deborah.Robinson2@wales.nhs.uk



APPENDIX 9

Participants Information Sheet: Carer Version

Participants Information Sheet: Carer Version



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Participant Information Sheet

Version 1.6 (18.06.2011)

Carer

Study Title: An Exploration of Clients' and Carers' Experiences of an Early Intervention for Psychosis Service (EIPS)

Researcher: Jessica Woolley

*I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. **One of the Early Intervention team members will go through the information sheet with you and answer any questions you have.** Talk to others about the study if you wish. (Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study). Please ask a member of the Early Intervention Team or contact me (Jessica Woolley) on the number provided overleaf if there is anything that is not clear.*

PART 1

Who is organising and funding the study?

I (Jessica Woolley, Trainee Clinical Psychologist employed by Cardiff and Vale University Local Health Board) am organising the research as part of my Doctorate in Clinical Psychology. There are no external bodies funding this study.

What is the purpose of the study?

The research aims to develop a better understanding of service users' and carers' experiences of an Early Intervention Service. It is hoped that this information will help the Early Intervention Service to develop in helpful ways.

Why have I been invited?

You are receiving this invitation because you are currently caring for an individual in contact with the Early Intervention for Psychosis Service.

It is hoped that at least 16 people (8 clients and 8 carers) will take part.

Do I have to take part?

It is up to you whether or not you decide to join the study. If you wish to take part I will ask you to sign a consent form to show that you have agreed to take part, and you will be given a signed copy of this to keep. You are free to withdraw at any time, without giving a reason. Whether or not you take part will not affect the services you receive from the Early Intervention Service.

What will happen to me if I take part?

If you agree to participate in this study I will meet with you in the local hospital outpatient unit or, if you prefer, at your home address, at a time convenient to you, to conduct an interview. This should take about an hour. During this interview, I will ask you to talk about your experiences and views of the Early Intervention Service and staff. There are no right or wrong answers. You will have full control over what is said, and can take a break and/or stop the interview whenever you need. The interview will be audio taped, with your permission, and at a later stage it will be transcribed. Any information that identifies you will be removed during transcription, and the audiotape will be destroyed immediately following transcription.

If you, and the person who is currently in contact with the Early Intervention Service, agree to take part in the study, you will be offered separate interviews on different days. The information elicited in each interview will not be disclosed in the other interview.

What are the possible disadvantages or risks of taking part?

During the interview, it is possible that recollecting or talking about your experiences may be upsetting. If you feel distressed, and want the interview to stop, we can terminate the interview at any time. A member of the Early Intervention Team will be contactable (by telephone) after the interview should you feel the need for additional support.

What are the possible benefits of taking part?

There are no direct benefits to you personally in taking part but the information you provide may assist in developing the service and enabling individuals and families using the Early Intervention for Psychosis Service to be better supported in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2 of this leaflet.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2 of this leaflet.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2**What will happen if I don't want to carry on with the study?**

You are free to withdraw from the study at any time. If you let me know, I will stop the interview or, if you decide to withdraw after the interview, I will remove the information that you have provided from the study.

What if there is a problem?

If you have a concern about any aspect of the study, please contact me (Jessica Woolley), xx (Clinical Lead for the Early Intervention for Psychosis Service in xx) or Professor Neil Frude (Senior Academic Research Tutor at South Wales Doctoral Training Programme for Clinical Psychology) via the contact details below. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from:

<http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx>. Telephone: 0845 120 3782

Will my taking part in this study be kept confidential?

Yes. All the information you give will remain anonymous and strictly confidential. All identifying information, such as your name, will be removed so you cannot be identified. Your signed consent form will be stored in a locked cabinet in Archway House (base for the Doctoral Programme in Clinical Psychology). However, if you disclose information that means that either you or another person are at risk this may mean I have to pass on the information to the relevant services in order for them to take the appropriate action. If such an eventuality were to occur this would be discussed with you.

What will happen to the results of the research study?

When the interviews have been conducted, I (Jessica Woolley) will analyse the data and report the findings. These will be submitted to Cardiff University as a doctoral thesis and may be published in a journal. If you would like a copy of the final paper or a summary of the findings, I would be happy to provide this. Audiotapes will be destroyed immediately following transcription, and the transcripts will be destroyed five years after the completion of the study.

Who has reviewed the study?

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Further information and contact details

If you would like to take part in the study, or if you have any questions/require further information, please contact me (Jessica Woolley) at the South Wales Doctoral Programme in Clinical Psychology, Archway House, 77 Ty Glas Avenue, Llanishen, Cardiff, CF14 5DX. Telephone: 02920 206464.

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Professor Neil Frude (Senior Academic Research Tutor at South Wales Doctoral Programme for Clinical Psychology): Archway House, 77 Ty Glas Avenue, Llanishen, Cardiff, CF14 5DX. Telephone: 02920 206464.

xx (Clinical Lead for Early Intervention for Psychosis Services in xx Local Health Board):
Early Intervention Team, St Cadocs Hospital, Lodge Road, Caerleon,, NP18 3QX

Many thanks for giving this invitation your time and consideration



1st Floor, Archway House 77 Ty Glas Avenue Llanishen Cardiff CF14 5DX

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Email/Ebost deborah.Robinson2@wales.nhs.uk



APPENDIX 10

Participants Consent Form

Participants Consent Form



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Centre Number:

Study Number:

Patient Identification Number for this trial:

Participant Consent Form

Version 1.3 (18.06.2011)

Study Title: An Exploration of Clients' and Carers' Experiences of an Early Intervention for Psychosis Service (EIPS)

Researcher: Jessica Woolley

Please tick each box

- | | |
|--|--------------------------|
| 1. I confirm that I have read and understood the information sheet dated 18.06.2011 (version 1.6) for the above study. I have had the opportunity to consider the information, and to ask questions, and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is entirely voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 3. I understand that the interview will be audio taped and the audio tape will be kept confidential. I confirm that I understand that the audio tape will be destroyed immediately | <input type="checkbox"/> |

following transcription.

4. I understand that anonymised data collected during the study may be made publicly available (through publication in a research journal), which I give permission for. I understand that all transcripts will be destroyed within five years of the study being completed. ☐
5. I agree to participate in the above research study. ☐
6. I confirm that I would like a brief report of the findings post study completion. ☐

Name of participant	Signature	Date

Name of researcher	Signature	Date

Copies: x1 to the participant; x1 to the researcher



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APPENDIX 11

Semi-Structured Interview Schedule: Client Version

Semi-Structured Interview Schedule: Client Version



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Semi Structured Interview Schedule

Client

(Version 1.5, 2.5.2011)

Warm up questions:

- How did you get here?
- Have you been in this building before? If so, how many times?

Stem interview questions:

- How did you first become involved with the Early Intervention Service?
How were you introduced to the service?
How did you feel about being supported by the service?
What were your expectations of the service?
Have your initial thoughts/feelings/impressions about the service changed since?
If so, why?
- Could you describe to me or tell me a bit about what it is like to be a client involved with the Early Intervention Service?
What do you think they (the Early Intervention for Psychosis Service) are trying to do? Please describe how and why.
What are the best/most helpful and worst/least helpful things about the service?
Do you have much contact with other clients who use the Early Intervention Service? If so, could you tell me a bit more about that?
What do other individuals who use the Early Intervention service say about it?
How often do you meet up with your care coordinator and your main carer

together?

Do you know whether or how often your carer meets up with the Early Intervention Service alone? If so, what thoughts/feelings do you have about that?

Do you have any ideas on what the service could do differently to support you?

- Could you tell me about the staff working at the Early Intervention Service?
What are they like?
How do they help you?
What do you like most/least about the staff? Or what do you find most/least helpful?
Have you had any involvement with the Early Intervention staff during periods of personal crisis? If so, has your impression of them changed since?
Would you like your relationship with staff members to be different? If so, please explain how and why.
- Could you tell me about your hopes for your future involvement with the early intervention service?

Expanding responses:

- Can you give me an example of that?
- Can you say any more about that?
- Is there anything else?

Exploring meaning:

- Why do you think that is?
- What thoughts/ideas do you have about that?
- What did that mean to you?
- How did that/does that make you feel?
- What did you/do you do about that?



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APPENDIX 12

Semi-Structured Interview Schedule: Carer Version

Semi-Structured Interview Schedule: Carer Version



SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Semi Structured Interview Schedule

Carer (Version 1.4 27.12.2010)

Warm up questions:

- How did you get here?
- Have you been in this building before? If so, how many times?

Stem interview questions:

- How did your relative/partner/friend and you first become involved with the Early Intervention Service?

How were you introduced to the service?

How did you feel about your relative/partner/friend being supported by the service?

What were your expectations of the service?

Have your initial thoughts/feelings/impressions about the service changed since?

If so, why?

- Could you tell me what it is like to be a carer of an individual supported by the Early Intervention Service?

What impact has the service had on you? Please describe how and why.

What do you think they (the Early Intervention for Psychosis Service) are trying to do? Please describe how and why

What are the best/most helpful and worst/least helpful things about the service?

Do you have much contact with other carers who support individuals who use the Early Intervention Service? If so, could you tell me a bit more about that?

What do other carers who support individuals in the Early Intervention service say about the service?

How often do you meet up and how often does your relative/friend meet up with the care coordinator?

How often do you meet up with the care coordinator alone?

Do you have any ideas on what the service could do differently to support you?

- Could you tell me about the staff working at the Early Intervention Service?

What are they like?

How do they help you?

What do you like most/least about the staff? Or what do you find most/least helpful?

Have you had any involvement with Early Intervention staff during periods of crisis for the individual you are caring for? If so, has your impression of them changed since?

Would you like your relationship with staff members to be different? If so, please explain how and why.

- Could you tell me about your hopes for your relative's/partner's/friend's future involvement with the early intervention service?

Expanding responses:

- Can you give me an example of that?
- Can you say any more about that?
- Is there anything else?

Exploring meaning:

- Why do you think that is?
- What thoughts/ideas do you have about that?
- What did that mean to you?
- How did that/does that make you feel?
- What did you/do you do about that?



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